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13. ABSTRACT (Maximum 200 Words) The goal of this program is to develop and recommend a model of care that enhances the quality of life for DOD children with life-threatening conditions and their families. Our strategy is to maximize current benefits and coordinate medical care with existing community resources and services, tailored to support the family's specified needs and requirements. The first year of work focused on a feasibility study to gather data on the intent, interpretation and implementation of the benefit; status of service delivery; available resources through the Military Health System, contract providers, community and other government agencies; and to conduct an assessment of needs of families. A distinct research protocol was designed to use individual interviews and focus groups to determine family and provider needs. The benefits likely to be used by military families and their children were analyzed. A data assessment collection tool has been designed to capture descriptors regarding community resources. The plan is to web enable the database in order to provide maximum availability and accessibility to the various potential users. An existing education curriculum for providers, Initiative for Pediatric Palliative Care, developed by the Education Development Center, was selected as one that best aligns with the CHI PACC® model.		
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INTRODUCTION:

For many reasons, current approaches to care for children with life-threatening illnesses leave children, families, and health care providers with unmet needs and unresolved quandaries. Children account for a relatively small percentage of all deaths in this country because of their general good health. The causes of death in children are substantially different from the causes of death in adults and vary considerably with age. Many children are born with rarely seen medical conditions, which create uncertainty in diagnosis, prognosis, and medical management. Therefore, limited knowledge and experience leave parents and health care providers unsure about how to provide care for these children. Even for common medical problems, children's general physiologic resiliency complicates predictions about survival and other outcomes.

Current insurance models for end-of-life care are based on a Medicare model for adults, and the requirements for these services severely restrict pediatric access. Due to third-party reimbursement and state licensing requirements, hospice programs generally must limit their populations to individuals expected to be within six months of death, who have elected to forego curative care and treatment. Few parents or physicians are willing to make such predictions and forego curative care for children. As a result, this stipulation restricts the availability of hospice services to children, given the numerous therapeutic options that are often available, as well as the unpredictability of the length of survival of this population. Parents, physicians, and other healthcare providers move from treatment and curative therapy to palliative care much more hesitantly with children than adults. There are few hospice programs dedicated specifically to hospice care for children and most programs are unable to address the unique needs of children and their families. Palliative care for children requires an integrated interdisciplinary approach among the child, the family and all providers of care and services that spans the spectrum of all the physical, emotional, psychosocial, and spiritual needs of children and families.

The goal of this program is to develop and recommend a model of care that enhances the quality of life for Department of Defense (DoD) children with life-threatening conditions and their families. This program model will be designed to integrate palliative care interventions along with therapeutic approaches to disease management from the time of diagnosis and to provide a smooth transition to hospice care when the child and family is ready to make that choice. Our strategy is to maximize current benefits and coordinate medical care with existing community resources and services, tailored to support the child and family's specified needs and requirements. Clear identification of required resources and services that are not available will allow the model to focus on needs that are unmet. The first year of work has been focused on a feasibility study to gather data on the intent of the benefit; the interpretation and implementation of the benefit; the current status of service delivery; the available resources through the Military Health System (MHS), TRICARE managed care support contract providers, and community and other government agencies; and an assessment of needs as perceived by families and healthcare providers in the MHS. The subsequent year will focus on data analysis; development of a model of service delivery; plans for implementation of the model for patient care; and tools for evaluation of the effectiveness of the model to include outcome measures of availability and accessibility to services, and patient satisfaction.

BODY: Research accomplishments related to objectives in the Statement of Work

OBJECTIVES:

1. Delineate the needs of children and families eligible for care in the MHS by gathering data from families at five military medical centers/clinics.
2. Delineate the educational needs of healthcare providers in the MHS by holding resident pediatrician and other healthcare provider focus groups at each location.

As background for these objectives, Children's Hospice International (CHI) researched, collected data, and analyzed the assessment tools, methods, and results of the assessments conducted by the CHI PACC® programs. This included a review of the initial assessment and analysis of structural barriers conducted by CHI, the focus group results from other CHI PACC® programs, and information published in the literature about needs assessments for this population. CHI provided a summary of how other CHI PACC® programs conducted focus groups and the kind of information that was gathered. This information was compiled and analyzed in a written report for the project team. Conclusions on the analysis of provider needs based on CHI's national assessment and the other CHI PACC® programs were included. (See Appendix 1)

Objectives 1 and 2 are encompassed in a distinct research protocol, for which the team members from the Uniformed Services University of the Health Sciences (USUHS) have the primary responsibility. This protocol requires approval by the institutional review boards (IRB) and, specifically, the human use committees (HUC) of the various medical treatment facilities (MTF) from which family members and providers will be recruited for participation in the focus groups. Most of the year has been spent on working the protocol through the various IRBs for approval. (See Appendix 2)

The following is the status of the IRB review and approval process to date:

- Approved by USUHS
- Approved by Malcolm Grow
- Approved by Walter Reed Army Medical Center (WRAMC) HUC, pending certain required revisions
- Reviewed by National Navy Medical Center (NNMC) IRB representative, with required revisions delineated.
- Reviewed by Ft. Detrick Human Subjects Research Review Board (HSRRB) and approved, pending certain revisions.

(See Appendix 3)

Ft. Detrick's HSRRB has agreed to designate USUHS as the IRB of record. A Memorandum of Agreement has been drafted, signed by the General, Ft. Detrick, and is pending the signature of the Acting President, USUHS. Once Ft. Detrick and USUHS finalize the protocol, this version will serve as the baseline for all others. Currently issues raised in all IRB reviews are being

addressed in order to work out all differences, which are primarily administrative and not substantive. As each institutional IRB grants approval, USUHS will review the documents. Ft. Detrick, as secondary reviewer, requires copies of all final approved documents prior to beginning to recruit participants from each institution. It is anticipated that actual data collection will begin in January-February, 2005. The first research activity will be the establishment of an advisory group of parents to provide recommendations about talking with other parents during focus groups and interviews

Points of contact on site at Keesler Air Force Base and Madigan Army Regional Medical Center have been identified. Preliminary discussions have begun regarding requirements for submission of the protocol to these institutions' IRBs.

3. Analyze existing MHS, TRICARE and community resources available to military families including current and potential providers of services and using parent, resident, pediatrician and subspecialty groups to identify unmet needs.

The actual health care benefits likely to be used by a military family and child with a life-threatening illness were analyzed with specific citation, description, definitions, and comments. Programs included in the analysis are Part 199.5 - TRICARE Extended Health Care Option, (ECHO), Home Health Care (EHHC) (Jul 28, 2004) and Part 199.4 – Basic Program Benefits. Where gaps were already known, they were listed. Benefits analyzed included respite care, home health care, custodial care, skilled nursing care, prescription drugs, dental care, counseling, bereavement care, care coordination, nursing case management, hospice, child life services at home, massage therapy, music therapy, acupuncture, durable equipment and durable medical equipment, structural alterations to dwelling, and transportation by other than ambulance. This analysis is currently being coordinated with the TRICARE Management Activity (TMA) representative on the project team. (See Appendix 4)

The population likely to be the target of this project is a subset of children with special health care needs (CSHCN). The Department of Health and Human Services, particularly the Division of Maternal Child Health, has promoted the delivery of family – centered, community-based services to CSHCN as a national agenda. The American Academy of Pediatrics supports this concept of family-centered, community-based care through their medical home initiatives. To be consistent with these initiatives, the community resource component of this project will incorporate considerations for non-medical resources that provide for the family's and child's needs for physical, emotional, educational, psychosocial, financial and spiritual support.

CHI provided summary data from other CHI PACC® programs to evidence what these programs have done to compile information on community resources. (See Appendix 5)

The Coordinating Center conducted an extensive literature review for community resources and assessment tools for community resources. (See Appendix 6) An important consideration for this literature review was to learn more about the broad subject of community resources and to

attempt to identify some answers to the following questions that would be considered in a new program model design. The questions are:

- What kinds of supports are available to children with life-threatening conditions and their families?
- Where is information about community resources located?
- What is the process for accessing community resource information?
- What are some of the barriers for families in identifying and finding resource information?
- What strategies can be incorporated in a new model design to optimize access to information about community resources?

The findings related to the literature search activity on community resources are as follows:

- Community Resource as a keyword search is too broad and yields an unmanageable number of responses.
- Utilization of the search word "hospice" or "terminal" yields only end of life services and does not capture resources that may support the chronicity of palliative care patterns.
- Health Science Library results yield little as to specific resources and application for service information that could be helpful to families searching for specific service delivery.
- There is an abundance of information available on the Internet contributing to results that are unmanageable due to an overabundance of information that is time consuming to sort through.
- Internet search results are limited by search words entered and may create barriers to families seeking information.
- Web sites that identify specific services and information vary on the elements of information provided.
- Some web sites do not indicate how current the information is and do not provide complete information about the resource such as funding for the service or the application process.
- Website searches provided voluminous amounts of information and a broader variety of possible resources.
- Local public library provides assistance with searches by librarian and does not require individual to have Internet search skills or access to technology to gather basic information.
- Some local public libraries have prepared information that can be accessed on county specific services and programs as well as information on some federal programs.
- Military library at Ft. Meade provided limited information on resources in the community and referred to the local public library system.
- Reliability of information received is inconsistent.

In summary, the findings of this review and search demonstrated some of the barriers families may be experiencing in identifying and locating potential community resources to support the

care of their children with complex needs. To date, other developing CHI PACC® models have incorporated care coordination as a core element in their proposed model designs to assist families with identifying and accessing appropriate community resources. The problems and barriers outlined above by TCC support a similar strategy of utilizing key professionals to assist families by conducting a holistic assessment of the family and child's needs, identifying and locating appropriate community resources, and coordinating and monitoring service provision.

See Objective 5 for additional information on the resource assessment tool and information on resources gathered to date.

4. Define eligibility criteria for the target patient population using information on target populations from other CHI PACC® projects, and applied appropriately for the DoD

CHI conducted research and analysis on identifying the potential target group and estimating the size of the group for the DoD population. These activities included:

- researching and compiling ICD-9 diagnosis codes used by the various CHI PACC® projects (See Appendix 7);
- reviewing the published literature on identifying and estimating the size of this population;
- analyzing the death data collected by the CHI PACC® programs;
- preparing a comparison spreadsheet estimating the size of the population of children served by the U.S. military who might benefit from CHI PACC® services (See Appendix 8);
- outlining a recommended process for the project to identify its target population and estimate the size of that group (See Appendix 9).

These documents have been most helpful in developing the questions for the initial data requests and analyses on the DoD population to be done through work with TMA. Dr. Thomas Williams, director of The Center for Health Care Management Studies within TMA, has agreed to work collaboratively with the project to assist in identifying a potential target population from within the MHS. Dr. Williams has access to data on health care provided within the MHS and the purchased care through the managed care support contractors, listed by diagnosis and utilization of services and resources.

The first step is to estimate the number of children with life-threatening illnesses in the DoD and outline the diagnoses and use of care and resources within the MHS. This population is likely to be the pool from which children, who meet the eligibility criteria for this project, will be drawn. The project team recognizes that all children with diagnoses that are life-threatening may not ultimately be eligible for this project. The severity of the illness and, therefore, the need for increasing resources to support the child and the family, may dictate a threshold of eligibility for the additional care and services recommended in the model design above that already provided by the current benefit.

The team has chosen to take a two-pronged approach to estimating and describing this population. A request was forwarded to Dr. Williams for data on children who have died before their 18th birthday during the past two calendar years in the NCA and in the entire DoD population. Data on these children will include all the ICD-9 diagnoses entered during the two calendar years prior to their death; all CPT codes entered during the two calendar years prior to their death; date of birth and death; and data that might serve as severity markers, such as rehospitalization, requirement for durable medical equipment, or home nursing care. The purpose of these data is to provide a retrospective estimate of children who might have benefited from this program. These data will be analyzed as case studies to estimate the potential number of children and to further describe this population.

A second approach will look at a current population of children with life-threatening illness as defined by predetermined ICD-9 codes and markers of the severity of illness, in part derived from the first population data analysis. These data may provide a different, and possibly more proximate, estimate of the population from which the pediatric hospice-eligible population will potentially be drawn. A draft of a table with conditions, ICD-9 codes, and severity markers was prepared and circulated to team members for comments. TMA will be asked to provide population data using this table. (See Appendix 10)

5. Design a resource assessment tool for identification of resources segments within a geographic community.

The Coordinating Center (TCC) has been primarily responsible for the design of a resource assessment tool. TCC reviewed existing internet sites that incorporated databases for community resource information and determined that, at this time, there is no existing resource assessment tool or a database that provides the kind of comprehensive resource information that this project anticipates is required. CHI's clinical consultant, Jeanette Osborne, presented information about the resource guide developed by the Kentucky CHI PACC® program. This guide was used to develop a list of data elements that describe the resources and these became the fundamental elements for data collection. (See Chart from Appendix 5)

The resource assessment tool that has been designed will serve as a template for identification of specified categories of resources and specific types of information on those resources in any community or geographic area. The purpose of the resource assessment tool is to ensure that data elements to be collected on resources are useful and captured through an organized method. The Resource Assessment Tool (See Appendix 11) has been developed for collecting such data. Each community resource will have the following elements of data collected:

- Type of resource - Category options are Provider, Community Resource, Medical or Funding
- Resource Name
- Contact Person
- Address/ Phone/ email
- Web address

- Office hours
- Languages in which info is available
- Military specific resource
- Wheelchair accessible
- Availability of transportation
- Daycare availability for siblings
- Cost of service
- Options for funding resource
- Eligibility criteria
- Application process and criteria
- Area served
- General comments

This data will be analyzed and compared to information gathered from family and provider focus groups with the goal of identifying potential gaps in community supports that could be beneficial to the proposed population for this project.

The resource assessment tool was tested for the ability of the tool to capture the resource information and for functionality of the tool. The assessment tool was tested on 100 resource records, representing community resources within the National Capital Area (NCA). Based on the initial data collection and review by the project team, modifications to the tool were recommended. One of the primary modifications was the addition of associated funding options. Following modifications to the assessment tool, the 100 resource records initially collected were re-verified and additional information added to promote data integrity and avoid null values in the final resource analysis. Data collection is currently underway and will continue through this phase of the project duration. There are currently 900 resource records collected for community resources.

6. Develop core and discipline-specific competency standards of care and training materials for providers for the target population according to CHI PACC® standards and in collaboration with WRAMC and USUHS to tailor those core competencies to meet the needs of the DoD target population.

Information on analysis of provider needs based on CHI's national assessment and the other CHI PACC® programs were included in the research and reporting activities accomplished under Objective 2. CHI reviewed the *CHI PACC® Standards of Care and Practice Guidelines* (See Appendix 12) and determined that they are generally useful for both military and civilian providers caring for a typical population of children with life-threatening illnesses. Assessment for compatibility with providers and the target population defined for this project will continue as the program develops.

CHI also conducted a comprehensive evaluation of existing provider education and training materials in the field of pediatric palliative care. CHI determined that it would be best to adapt an existing curriculum that best aligns with the CHI PACC® principles in content and theoretical

approach, rather than develop and create a completely new education and training program. CHI has selected the curriculum of the Education Development Center (EDC), Initiative for Pediatric Palliative Care (IPPC), as the most appropriate for all the CHI PACC® project, to include the DoD project. CHI is currently negotiating with EDC to finalize its contract and statement of work with EDC to evaluate and adapt provider education materials for the DoD project.

7. Construct a database to include resources available to military families and plan a design for a user-friendly method for military families and providers.

The ultimate plan for this aspect of the project is to web enable the resource assessment tool and the resource data elements collected in order to provide the maximum availability and accessibility to the various potential users. The design of the system will incorporate the ability to analyze various aspects of the information, to include an assessment of the quality of the data and how it is used. Specifically, tools will be designed to validate the accuracy of the information provided, to invite family feedback on their experiences with the resource, and to generate reports regarding other outcome measures as yet to be determined. This phase of the project is just beginning.

Features have been identified, through the review of web sites that incorporated resource information that may be considered to provide optimal usability and functionality by the end user. In addition, some mechanism to evaluate website information is essential to ensure the quality of information found on various sites. A universally recognized standard for responsible self-regulation of healthcare information is set forth in a tool called Health On the Net (HON) code. The HON code defines a set of voluntary rules designed to ensure that a reader always knows the source and the purpose of the information he or she is reading. These guidelines encourage the authority, confidentiality, proper attribution, justifiability and validity of the medical advice and information provided (<http://www.hon.ch/Project/HONcode.html>.) These guidelines should be considered when healthcare information is researched and provided through this web site.

Attention to the identification of opportunities that can capitalize on relationships within existing "micro-system" components can optimize the well being of people who are currently served by the system of care. This principle is consistent with the concepts outlined in the Institute of Medicine Report, "Crossing the Quality Chasm". Therefore, in anticipation of a potential partnering with a preexisting and funded program with the DoD, a process review was performed and documented for Military One Source. The review was based on their current involvement with the military system to identify opportunities to leverage system improvement related to community resources for the anticipated population for this project. After reviewing Military One Source, The Coordinating Center wrote the following considerations and recommendations for the project team to keep in mind when developing a CHI PACC® model for the Military Health System:

- Incorporate use of the Military One Source program in future program model to support access to military and community resources as well as general educational information on family related topics.
- Identify information topics that apply to children with life threatening conditions for inclusion in Military One Source databases.
- Collaborate with Ceridian to incorporate publications that target the needs of children with life threatening conditions, specifically including CHI publications relating to palliative care.
- Identify additional resource linkages to Military One Source that are specific to the children's hospice/palliative care population.
- Offer training for Military One Source supervisors, consultants (general and specialist) and researchers regarding this specific population.
- Consider reporting needs for this population and collaborate with Ceridian to submit reports for targeted population.
- Incorporate Health on the Net Code Guidelines related to the distribution of medical and health specific information to ensure credibility and quality.
- Identify any issues related to HIPAA regarding the distribution of resource or health information as it relates to model/program design.
- Educate families participating in the project on the benefits of a telephonic mode to promote comprehensive response to the needs request.
- Address the gap regarding accessing services as it relates to the education and resource information role of Military One Source vs more intensive care coordination.
- Develop a means to measure outcomes related to the use of Ceridian services with this population.

See appendix 13 for the full report and the data flow diagram for consideration under future model design. Meetings are scheduled for January 2005 to identify additional military support programs that will be analyzed for opportunities to incorporate existing resources into the new model design.

Proposals have been solicited for the development of a web based output database design. The process is currently on hold until the interface or collaborative partnering with other military system options has been fully explored. This is anticipated in the 1st quarter of 2005.

8. Evaluate existing models of care coordination, incorporating the CHI PACC® standards, to determine how to merge the best components of each model into the new CHI PACC® military model for care coordination.

As part of the model development, it is planned that the scope of services recommended by the national CHI PACC® will be incorporated into the recommendations for the military CHI PACC® model. To date, there are no existing functional programs in any of the states that have completed a model design or implemented the CHI PACC® philosophy of care for this population.

Initial steps towards the development of a model for this population involved an analysis of the typical processes used by an individual to identify and access a resource. (See Appendix 14) The purpose of this analysis is to identify possible areas of vulnerability that may preclude completion of this identification process from the recognition of the need to the point of service delivery. This analysis will be considered while developing the new model of care for children in the military. In particular, quality measures will be incorporated into the process to minimize the potential for unsuccessful service delivery. For any typical request for resources, a professional, nonprofessional or family member may identify a need for a community resource. Then, there is some research done to identify a source for the needed resource to yield potential options to meet the request. This research can be done by the requestor or by another third party, who could be anyone invested in supporting the request. In most situations, there is some referral or application process required for accessing the resource. The referral or application process can vary from providing basic demographic information to extensive financial and medical reviews prior to the approval for the resource requested. Depending on the type of resource, some situations will warrant the identification of a provider to deliver the service. In some situations, further research will be necessary to locate funding prior to service delivery. Subsequent to approval for the resource, identification of the provider, if applicable, and identification of a funding mechanism for the service delivery would occur. In some situations, reimbursement is requested following service delivery.

The basic tasks identified in this process are:

- Identification of a resource need by family, professional or other nonprofessional
- Research for possible options for desired resource
- Application to obtain resource
- Identification of a service provider
- Locating a funding source
- Delivery of the service
- Reimbursement for the cost of the service or resource

Each task within the process has been analyzed to identify vulnerabilities in the process that require incorporation into the projected model of care. Metrics that quantify successful resource access shall be considered as a quality monitor in the new program design.

9. Analyze data obtained from the family and provider needs assessments to map the networks of services and informal social support used by families in each geographic area and to determine the best design in applying the CHI PACC ® model to a program for military children and families.

Work on this objective is contingent upon completion of many of the previous objectives.

10. Design a DoD quality assurance program that is consistent with all state CHI PACC programs by developing basic components for quality monitors, minimum data sets, a computerized tracking system and an overall program monitoring system.

CHI has spent a considerable amount of time investigating existing evaluation and quality assurance programs in pediatric, palliative, and end-of-life care for use with the CHI PACC® programs. While some existing programs might serve as models for the development of a CHI PACC® quality assurance program, none examined thus far can be deemed a perfect fit. For the purpose of assuring quality, CHI PACC® approach is unique in that it blends curative treatment and palliative care, provides continuous service provision from the time of diagnosis through cure, maturity, or death, and involves multiple providers in the provision of care.

CHI conducted a thorough review of the 2003 Second Edition of the CHI PACC® Implementation Manual and began to outline recommended revisions to the publication to make the resource a user-friendly manual that provides concrete how-to information and tools to benefit the DoD project and other developing CHI PACC® programs. Some of these implementation guidance materials were provided to members of the DoD CHI PACC® project team.

In addition, CHI reviewed and collected articles related to the evaluation of pediatric care through a review of resources on the internet. This literature review was used to develop a matrix of outcome measures applicable to all CHI PACC® programs, including DoD, based on the teamwork and discussions from the CHI PACC® demonstration program meeting in May 2004. This document (See Appendix 15) also outlined proposed categorical outcomes, outcome indicators, data sources, and collection methods that will be applicable to all CHI PACC® programs, including DoD.

CHI held a conference call with the Centers for Medicare and Medicaid Services (CMS) to develop a strategy for conducting evaluations of CHI PACC® programs that will include the DoD project. All parties agreed that a potential first step would involve testing a family satisfaction instrument developed by Jeanette Valentine of the University of Washington. This instrument has not yet been provided to or reviewed by the project team. This work will be continuing to be on-going.

KEY RESEARCH ACCOMPLISHMENTS:

- The status of the IRB review and approval process of the research protocol on focus group assessments of parents and health care providers to date:
 - Approved by USUHS
 - Approved by Malcolm Grow
 - Approved by WRAMC HUC, pending certain required revisions
 - Reviewed by NNMC IRB representative, with required revisions delineated.
 - Reviewed by Ft. Detrick Human Subjects Research Review Board (HSRRB) and approved, pending certain revisions

- USUHS has reviewed and analyzed the current and proposed Tricare benefits listing specific citation, description, definitions, and comments. Gaps were listed, where they were already known.
- TCC has designed a resource assessment tool to serve as a template for collecting information on resources and is currently collecting data on resources and services in various categories throughout the NCA.
- TCC is in the preliminary stages of designing how the resources database will be used and maintained and where it will be housed.
- Dr. Thomas Williams, director of The Center for Health Care Management Studies within TMA, has agreed to work collaboratively with the project to identify a potential target population from within the MHS. Several research questions for data on the potential target population are under consideration.
- CHI has selected the curriculum of the Education Development Center (EDC), Initiative for Pediatric Palliative Care (IPPC), as the most appropriate for all the CHI PACC® project, to include the DoD project.
- CHI reviewed and collected articles related to the evaluation of pediatric care through a review of resources on the internet. This literature review was used to develop a matrix of outcome measures applicable to all CHI PACC® programs.

REPORTABLE OUTCOMES:

None at this time

CONCLUSIONS:

The original proposal and objectives for this project were written three years ago. As the work progresses, it is clear that this project is a vital and evolving one. Clarification of the original intent, new and expanded dimensions of the scope of the project, and the potential for various interfaces with existing programs and interests within the DoD have emerged from the current, on-going efforts. The ultimate focus of the project has not changed. Efforts will continue in line with these current objectives, as well as work on the new objectives resulting from the additional resources from FY 04 appropriations. These next steps are in line with the current and new FY 04 objectives plus some important links and strategies that have resulted from the past year's work.

- The first research activity will be the establishment of an advisory group of parents to provide recommendations about talking with other parents during focus groups and interviews. This should begin in January – February 2005.
- Work on the analysis of the benefit will continue with TMA, especially as the new benefits under ECHO are implemented. A briefing with the Assistant Secretary of Defense for Health Affairs is planned

- Discussions have begun with key representatives of family programs and children and youth services from the Office of the Secretary of Defense, Military Community and Family Policy, as well as Military One Source. The purpose of these interfaces is to identify areas of common interest in support of military families and to avoid duplicative efforts.
- Data collection and analysis on the potential target population within the DoD will proceed in collaboration with Dr. Thomas Williams, director of The Center for Health Care Management Studies, TMA. These data sets will be used to estimate the size of the population and develop specific eligibility criteria.
- CHI is scheduled to complete contract negotiations with EDC to begin work to evaluate and adapt provider education materials for the DoD project. Other areas of education and training for this project will be identified once the parent and provider needs assessment group data becomes available.
- Proposals have been solicited for the development of a web based output database design. This is anticipated in the 1st quarter of 2005.
- The first step in the development of a quality assurance program will involve testing a family satisfaction instrument developed by Jeanette Valentine of the University of Washington, as proposed during a conference call with the Centers for Medicare and Medicaid Services (CMS). Further discussions are planned with CMS as the work on the quality assurance piece develops.

APPENDIX 1

CHI PACC® Needs Assessments for the DOD mCare Project

Children's Hospice International – Z. Saunders

July 15, 2004

CHI and the CHI PACC sites conducted a variety of needs assessments beginning in 1997 to identify problems in the current system of care for children with life-threatening conditions and their families and how best to address these to improve the quality and delivery of care.

Nationwide System and Structural Barriers

In 1997 CHI convened focus groups representing hospitals, home health and hospice agencies, public agencies, and professionals to identify system and structural barriers to optimal care for children with life threatening conditions that might be addressed in the design of the CHI PACC model

These barriers included

- Admission to a hospice requires life expectancy of 6 months or less
- Admission to hospice means hope is abandoned
- Family must choose between hope for cure and supportive care
- Reimbursement is not available for respite, bereavement, expressive therapies
- Care is uncoordinated and there are gaps in the continuum of care
- Admission of pediatric cases is discouraged because of the expense

The system barriers lead to:

- Crisis driven and high cost care
- Institutional focus that results in ineffective and wasteful use of resources
- Disruption in family life, cohesion, resources that results in increased social cost
- Difficult access because of regulations and reimbursement restrictions
- Lack of early preparation for and access to end of life-care for the whole family.

Quality of Clinical Practice

Through a series of other meetings and discussions with similar groups, CHI identified problems in the current clinical practice for children with life-threatening conditions. These problems were addressed in the development of the CHI PACC Standards of Care and Practice Guidelines. The identified problems were organized as follows;

The Goals of Care:

- Plan of care specific to provider rather than consistent across all settings and providers.
- An almost exclusive focus on medical care in the acute care setting, while ignoring palliative care needs.
- Family and child often not included in care planning

Integration of Disease Treatment and Symptom Management

- Unreliable and inconsistent assessments.
- Inadequate and ineffective symptom management and frequent failure to include family in decision making.
- Inconsistent availability of on-call medications in the community.

Advance Care Planning

- Discussions with parent and child on disease progression, treatment choices often do not occur.
- Child and parent choices are often ignored.
- Advance care planning often limited to signing a DNR form.

Coordination and Continuity of Care

- Medical records not available after hours
- Long waits for urgent care.

- Difficult transfers in the last weeks of life including disruptions in medication.
- Care for multiple illnesses often fragmented

Patient/Family Support

- Children/families feel alone, confused, and helpless.
- Care is not individualized
- Cultural sensitivity is lacking.
- Children and families feel uncomfortable raising important concerns.
- Bereavement counseling and follow up is rare.
- Families must assume heavy financial burdens.

Care During the Time Near Death

- Contact with the care team is cut off after death.
- Family and child are not given realistic information about the disease trajectory.
- Symptoms near death are often endured rather than suppressed.
- Family and child's wishes regarding place and circumstances of death are often ignored.

State and Local Service Availability and Support

The CHI PACC sites also conducted needs assessments in their state and local areas in preparation for the design of their service and delivery package for children with life-threatening conditions. Although the primary focus of the CHI PACC programs is the Medicaid population, most of the needs assessments addressed a broader population including children covered under private insurance plans.

Utah conducted three different focus groups at two locations with parents of children who had died of a life-threatening condition within the past four years. Utah also conducted interviews with parents who were unable to attend the focus groups. The parents of 40 children were involved in the focus groups and interviews.

Kentucky contracted with another organization to conduct focus groups of parents who had children with life-threatening conditions, including those whose child had recently died. About 23 parents participated at five different locations.

In both Kentucky and Utah, parents were asked to discuss their experiences with the health care system from the point of diagnosis to bereavement including what was helpful and not helpful to them, and their suggestions for change. The major themes and concerns expressed by the parents in both Utah and Kentucky are summarized below.

Diagnosis/Information

- Families did not have adequate information about treatment options, the course of the disease and what to expect.
- Written and comprehensive information packets would have been helpful.
- Information and resources were more widely available to families whose child was diagnosed with cancer.
- Many parents sought and wanted to be linked to other parents who had experienced the same issues. Hospitals did not promote these linkages.
- Most indicated they wanted the physician to be frank and honest while maintaining a hopeful attitude.
- A number of parents expressed surprise that busy and important specialists took a personal interest in their child's welfare. Frequent calls, availability to answer questions, and support of the child and parent's choices demonstrated caring.

Care Coordination

- Families were often the primary coordinator of their child's care and none believed they received comprehensive case management that addressed medical, social, financial, and emotional aspects of their child's care. Care was often fragmented.
- Social workers who traditionally play this role were called in only when there was a crisis that the medical team did not want to address. Thus families felt no special rapport with the social worker, particularly in the hospital setting.
- Parents resented being asked the same questions over and over again, particularly when it seemed irrelevant or was already in the record.
- When multiple specialists were involved, it was difficult for parents to reconcile the different recommendations—"none of the doctors wants to take responsibility for the whole child."
- The child's pediatrician, who made the initial referral was usually out of the loop and was not necessarily interested in continuing to be involved.
- Coordinating with the child's school was often difficult and frustrating.
- Child and family in rural areas had the most difficulty accessing services and maintaining continuity of care.

Treatment – Hospital

- Medical practitioners ignored or failed to respect the parents' knowledge of his/her child.
- When treatment protocols were exhausted and child was considered terminal, the child and family felt abandoned by the medical team for there was often no further contact with this team.
- Families had difficulty generalizing about the quality of nursing care in the hospital because it was inconsistent and varied as much as the nurse on duty. Although some nurses were highly praised, parents felt they had to be vigilant to prevent medication and other errors
- Rules in the newborn intensive care unit made it difficult for parents to care and bond with their infant.
- The family of the child who required frequent hospital visits experienced many hardships related to child care, transportation and lodging costs, missed work, etc. and there were few resources available to help them.
- Hospital had few accommodations for parents who wished to stay with their child
- Although parents were trained to use equipment in the hospital, this equipment was not always the same equipment brought to their home.
- Many parents indicated they wanted to have more instruction in reading charts, vitals, labs, and pain symptoms so they could be more effective in monitoring their child's progress and care.
- Some parents felt their child was being treated as a guinea pig and they would have chosen to follow a different course had they been given more information.

- Families were frequently dissatisfied with care received in regional or community hospitals. Emergency room visits required long waits and staff was described as callous, inattentive, inexperienced, incompetent or arrogant.
- Parents recommended that medical staff including nurses receive sensitivity training.
- Almost all the families whose child had experience with child life specialists valued these contacts.

Home/Hospice Care

- Of all the services used during the course of their child's illness, families indicated the greatest satisfaction with home health or hospice care. This was the most critical service in helping them cope with their child's illness.
- Most families had no idea how much time and effort would be required to care for their child at home, including the performance of complex medical procedures. Training usually was begun at the hospital, just before discharge. Parents indicated they would have welcomed instruction earlier while their child was still in the hospital.
- The home health/hospice nurse was viewed as the "life line." They were often seen as a teacher, a surrogate parent to the parent, an advocate for the child, a shoulder to cry on, and the go between among all the other professionals who were involved. Since these individuals are pivotal in helping the family cope with the most painful experience of a life time, they must be exceptional. A positive relationship helps ease the pain for the child and all family members, while a negative relationship exacerbates the pain. Negative experience was more often encountered with agencies without pediatric expertise.
- Having to change home health or hospice provider because of a change in health insurance coverage, or other external circumstances usually resulted in a hardship for the child and family.
- All families needed some respite, but respite care was available to very few families. Many reluctantly relied on extended family to provide respite care. Employers who allowed parent to go on a flexible schedule were greatly appreciated.

Death/Bereavement

- Although the child's death was not unexpected, the timing of the child's death often was. Many parents felt they did not have adequate preparation or understanding of the dying process, even those with access to hospice.
- The opportunity to be close to their child and have other family members present, whether the death occurred at home or in the hospital was important for all families giving them a sense of control and closure.
- Many were overwhelmed by funeral arrangements, accommodating out-of-town family, calling the pharmacy and others involved in the child's care to notify them of the death.
- Many families relied on informal counseling provided through their church community to help them through bereavement, but often found this support inadequate though well meaning.
- Families did not value social workers who were sent in to provide counseling, after the fact, who were not part of the care team.

- Many families expressed appreciation for the doctor and nurse who acknowledged their child's death. When their child died, the support systems also vanished, magnifying the loss.
- Families who had access to the community and hospital-based bereavement newsletters, events, counseling found these helpful.
- Although grief counseling was available, it was not always accessible to other family members and siblings. Some indicated they needed counseling beyond the one-year deadline.
- All families attempted to make meaning of their loss from making donations to disease organization, to participating in memorial services, to writing about and sharing their experience, to joining support groups to help other families.
- Families with other children, expressed regret in not being able to meet the emotional needs of their other children during the illness. Marital problems and divorce occurred in some of the families.

Financial

- Health insurance generally covered most of the child's medical expenses, but some insurance carriers did not provide adequate coverage for home care.
- Some families were stretched financially or on the verge of bankruptcy, either because they gave up a job to qualify for Medicaid, to care for their child, or because of other expenses related to the illness.
- All families expressed frustration in dealing with insurance carriers. The companies seemed impenetrable and decisions seemed arbitrary. Navigating coverage issues, sorting incorrect claims, always with a different person was a full time job by itself. A few enlightened companies assigned a case manager, but this did not always help.

Services Needs and Gaps Assessment

Utah asked parents who attended the focus groups to rank the availability and adequacy of a list of services. The responses helped the Utah PACC program design its package of services.

RANKING OF SERVICES BY ALL RESPONDENTS

TIER	RANK	SERVICE	Availability Score (%)	Adequacy Score (%)
1	1	Insurance Coverage for Medical Services	100%	65%
2	2	Home Health / Nursing Care	91%	67%
	3	Medical Supplies and Equipment	95%	80%
	4	Case Management or Care Coordination	82%	53%
	5	Home Care Instruction for Parents	86%	74%
3	6	Pharmacy Services	90%	63%
	7	Pain and Symptom Management	81%	75%
	8	Spiritual Support	76%	87%
	9	Financial Information or Help	41%	36%
	10	Help in Navigating Insurance Coverage	23%	27%
	11	Information and Referral Services	76%	40%

	12 Bereavement Counseling	86%	67%
	13 Parent & Family Counseling & Support	77%	56%
	14 Parent-to-Parent Support	57%	29%
	15 Respite Care	53%	67%
	16 Home Therapy [e.g. Physical Therapy]	60%	67%
4	17 Housekeeping Help	23%	57%
	18 Play, Art & Music Therapy for the Child	53%	67%
	19 Child Care for Siblings	22%	14%
	20 Physician Home Visits	24%	38%
	21 Play, Art & Music Therapy for Siblings	40%	38%
	22 Transportation Assistance	6%	0%
	<input checked="" type="checkbox"/> Home Modifications	19%	33%

New York State conducted their needs assessment through a web-based concept mapping system that provides a "more rigorous statistical basis for modeling needs." In phase one, a group of advisory committee members participated in a brainstorming session to generate need statements. These were entered into the data base and then 12 advisory committee members were instructed to log on to the site and sort the items. Following the sorting, the importance was rated by the members on a scale of 1 to 5. This phase was then extended to colleagues who did the same.

The results of the brainstorming resulted in 74 unique needs statements contributed by 50 experts in pediatric palliative care. Children's needs were placed in major clusters and ranked. The 10 highest-rated individual needs statements are shown in the cluster categories in the table below.

Major Clusters	10 Highest Cluster Ratings	Achievement Feasibility
Dignity-respect	2	*
Physical Support (Comfort)	4	*
Psychological Support	2	
Family Support		
System Access and Delivery	2	

A summary of conclusions from their report includes the following:

Dignity-respect "dignity and respect deserve attention from program planners and evaluators as central aspects of a child's life that should receive explicit attention in program planning and evaluation."

Physical Comfort The two highest ratings were "effective pain management" and "consistent pain assessment."

Psychological Support One third of the needs statements generated by experts reflected this item and include statements such as "love, access to peers, and fun." They concluded "program planners may want to consider this as separate dimension in the assessment of child and family needs."

Family Support Needs This cluster varies with the individual family circumstances, geography, number of siblings, etc.¹

Service System Access and Delivery The top two items in this cluster included the barrier imposed by the 6-month limit on hospice and access to palliative care benefit from the time of diagnosis

Survey of Utah Pediatricians

Utah also surveyed pediatricians at their annual meeting in Salt Lake City 2001 using an electronically administered survey to determine their training and information needs regarding children with terminal conditions. About 100 responded to the survey.

Results of Survey of Utah Pediatricians - June 2001

Questions	% Agree or Strongly Agree
1. I feel comfortable managing the terminal phase of my patient's illness.	40%
2. I would benefit from additional training/education in pain and in the management of pain and other symptoms during the terminal phase of illness.	79%
3. I would find it helpful to have more information about existing resources available to support families with a child with a life-threatening illness	90%
4. I am comfortable coordinating the communication between specialists and my patient when complex end-of-life issues arise	58%
5. My patients with terminal illness and their families need better access to support services than they are generally able to access under our current system of health care delivery and financing.	66%

Other Parental Assessment of the Quality of Pediatric Palliative Care

Other researchers have attempted to assess parents experience regarding end of life care. Meyer² surveyed parents of 56 children who had died between 1994-1996 in the pediatric intensive care unit at two Boston hospitals. Contro³ interviewed 68 family members of 44 deceased children.

Meyer concludes "parents place the highest priorities on quality of life, likelihood of improvement, and perception of their child's pain when considering withdrawal of life support. Parents make such decisions and garner psychosocial support in the context of a social network that changes over time and includes health care professionals, family, and friends." Recommendations include

1 It is interesting to note that this cluster did not include any of the highest ratings. If parents and children had been included in the ratings, the results may be different. Although there had been plans to have parents and children participate in the web-based ratings, this has not occurred to date.

2 E. Meyer et. al, "Parental perspectives on end- of- life care in the pediatric intensive care unit," *Critical Care Medicine*, 2002, Vol 30. No. 1. pp 226-231

3 N Contro, et al, "Family perspectives on the quality of pediatric palliative care. *Archives of Pediatrics and Adolescent Medicine*," Vol 156, No. 1, January 2002

- Encouraging parents to share their views on withdrawal of life support to foster dialogue between parents and staff.
- Child's quality of life, likelihood of getting better, perceived pain, and likelihood of survival need to be regular topics of discussion.
- Optimize the child's pain management and educate parents about how pain is assessed and relieved.
- Educate parents about infrastructure of the health care team including who can best address their questions
- Facilitate the involvement of community pediatricians, religious support persons, and palliative care programs during the hospitalization as a means to improve emotional support and continuity of care.

The Contro study identified several areas of unsatisfactory interactions with staff: "confusing, inadequate, uncaring communications regarding treatment or prognosis, preventable oversights in procedures or policies, failure to include or meet the needs of siblings and Spanish speaking family members, inconsistent bereavement follow-up." The study also found a discrepancy between the high degree of pain and a perception that pain had been managed well.

Summary

CHI and the CHI PACC sites have used a variety of needs assessments including surveys, interviews, focus groups, and web-based and electronic surveys and mapping to help design system and program structure, scope of services, and identify training needs and approaches. Parents and professionals participated in these surveys and also helped develop and refine the instruments.

Obviously, the design and form of the instruments used by the *mCare* project will be driven by the purpose of the assessment. Although the results of the assessments done by CHI, the CHI PACC sites, and others have common themes, it will be important to articulate clearly how *mCare* plans to use the results and information learned before it determines how best to structure the assessment. It may use assessments to identify structural barriers in the military health system, service gaps, how information flows, professional training needs, etc. The results of similar assessments conducted by others will help inform the final design, but cannot substitute for assessing the needs of military families who have a child with a life-threatening condition.

APPENDIX 2

PROPOSAL FOR A NEEDS ASSESSMENT FOR mCARE (MILITARY CHILDREN AT RISK—ENHANCING QUALITY OF LIFE) PHASE II

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**Proposal to collaborate in project submitted as USAMRMAA Proposal for Children's Hospice,
Phase II, FY 04 funds**

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Abstract

Children with life-threatening illnesses and their families require a coordinated network of services involving health care, community resources and informal supports. For active duty and retired military families, this occurs in the context of the TRICARE benefit, resources and needs of the military community, and the various and changing civilian communities in which military families live.

This proposal describes Phase II of a needs assessment of military families with children with life-threatening illnesses, using a case study methodology. Phase I of the study (previously funded) includes case studies for the National Capital Area (NCA) and Keesler AFB. Phase II will include case studies of the areas surrounding the Madigan Army Medical Center, Naval Medical Center, San Diego Munson Army Health Clinic at Ft Leavenworth, Kansas. Altogether, there will be case studies of the NCA, areas surrounding installations with major medical centers for the Army, Navy and Air Force, and the area surrounding a small installation with limited services available through the direct-care military health system. At each site, data collection will include interviews and/or focus groups with parents, interviews and focus groups with health care providers, and collection of TRICARE data regarding case management and utilization of care. Three existing surveys (the FACCT End-of-Life Survey, Medical Home Assessment Tools, and a survey of the quality of life of caregivers previously developed by the investigators with parent advisors), consultation with the mCARE project team and consultation with parent advisors will provide the basis for interview and focus group questions. Needs identified will be compared to the services available at each site and then to the services covered by the TRICARE benefit (as analyzed in Phase I of the needs assessment). In collaboration with other partners in the mCARE project, needs identified by parents of children with life-threatening illnesses and health care providers who provide care for them will be compared to services provided by the military health care system, the TRICARE benefit, and community resources. The assessment will also describe access and barriers to access for services from these three sources. Subsequently, the mCARE project team will propose a model of care for military children and their families that will provide a coordinated, comprehensive, family-centered approach to care from the time of diagnosis of a life-threatening illness through the time of bereavement of families.

This proposal also adds the following components to the needs assessment as described in the Phase I proposal: development of an advisory group of parents in the National Capitol Area, a collaboration with Family Medicine, adaptation to this population of a previously-developed measure of quality of life of caregivers, technical assistance in defining eligibility criteria, and participation in evaluation of program components piloted by other mCARE project team members (respite care and/or care coordination).

Background and Significance

The 2000 National Home and Hospice Care Survey, a survey of home health agencies and hospices that included patients of all ages, found 64,000 patients under 18 years of age (4.7% of the population served) received home health and hospice services in 2000, representing a rate of 8.8 per 10,000 in the civilian population of the U.S.¹ However, current insurance and delivery models are based on a Medicare model for adults, and few pediatric home and hospice care programs are available. A recent report from the Institute of Medicine emphasizes the importance of improving palliative and end-of-life care for children and families, and calls for research regarding models of care and ways to measure outcomes.² Children with life-threatening illnesses and their families require a coordinated network of services involving health care, community resources and informal supports. For active duty and retired military families, this occurs in the context of the TRICARE benefit, resources and needs of the military community, and the various and changing civilian communities in which military families live. The current proposal sets forth the plan for Phase II of a needs assessment/feasibility study for the military population of children with life-threatening illnesses—a part of a larger Congressionally-funded feasibility study to develop an effective model of care within the Military Health System (MHS) and the TRICARE benefit, coordinated with available community services. The larger study is based on a partnership between Walter Reed Army Medical Center, the Uniformed Services University of the Health Sciences, Children's Hospice International (CHI) and the Maryland Coordinating Center (MCC) (the mCARE partners).

Phase I of the needs assessment addressed the following technical objectives:

Technical Objective 1:

Delineate the needs of children with life-threatening illnesses and their families who are eligible for care in the Military Health System (MHS).

Technical Objective 2:

Delineate the educational needs of pediatricians (pediatric residents, general pediatricians and pediatric subspecialists) that relate to providing and coordinating care for children with life-threatening illnesses and their families.

Technical Objective 3:

Analyze the TRICARE benefit and services provided by the MHS in relation to the needs of children with life-threatening illnesses and their families.

Technical Objective 4:

Develop recommendations for a program to provide health care and services to military children with life-threatening illnesses and their families.

This proposal is for Phase II of the needs assessment, which will be completed in collaboration with the mCARE partners. Phase II overall will address the following goals:

Goal 1: Expand the needs assessments of family members and providers to include additional off-site locations. Modify the needs assessment template developed from NCA and Keesler Air Force Medical Center findings based on experiences at the additional sites.

Since the original development of this plan, there have been major changes to the timelines of the various components of the project. Some of the changes are due, in part, to the length of time from conception and project design to the awarding of the contract and the subawards, approximately 1 year. Due to slippage of the timelines, there were changes in the availability of certain key personnel and associated increases in costs, necessitating a complete revamping of the USUHS budget. In addition, requirements for approval through several institutional human use committees prior to conducting the focus groups dictated that the case studies be limited to those obtainable in the NCA and at Keesler Air Force Base. Therefore, plans for case studies at three other sites, and the

integration of information from all 5 sites, have been moved to Phase II and are described in this proposal.

Goal 2: Define the eligibility criteria for the population of children to be served.

Although this was listed as a goal in the original proposal, it has become clear that a systematic method of identifying and classifying the population using objective criteria would provide the best framework for obtaining consistent and measurable outcome data, especially for cost.

Goal 3: Develop a framework for datasets to support the new model design

Goal 4: Develop a plan for a flexible website for multiple user groups that houses the various datasets discussed in goal 3.

Goal 5: Develop a plan for the education of families.

Goal 6: Design a new model of care with cost projections in preparation for implementation and cost analysis.

Goal 7: Develop implementation strategies for the new model design.

Goal 8: Design a methodology and conduct a pilot study to evaluate certain identified components of the new model design, e.g. respite care, care coordination. The evaluation should address strategies for implementation of these components.

The research described in this proposal primarily falls under goal 1. The results of the research will be applied to the work of goals 2-8, with USUHS personnel participating in the ways described below.

Preliminary Studies

Phase I of the study includes case studies for the National Capital Area (NCA) and the Keesler Air Force Base. The data from these two case studies, and the needs assessment template designed for them, will inform Phase II case studies of the areas surrounding the Madigan Army Medical Center, the Naval Medical Center, San Diego Naval and Munson Army Medical Clinic at Ft Leavenworth, Kansas. At each site, data collection will include interviews and/or focus groups with parents, interviews and focus groups with health care providers, and collection of TRICARE data regarding case management and utilization of care. Needs identified will be compared to the services available at each site, and then to the services covered by the TRICARE benefit (as analyzed in Phase I of the needs assessment). Other relevant preliminary studies of the principal investigator and co-investigator include the following:

- *Quality of Life of Caregivers of Children with Special Health Care Needs, A Survey Developed Collaboratively with Parents.*³ A copy of this survey appears in Appendix 2. A group of parents of children with special health care needs collaborated in determining the domains of the questions in this survey, as well as in writing the questions and descriptors.
- Focus groups with parents and patients about evidence-based medicine.⁴ These groups pursued a preliminary exploration of what parents and patients understand about medical evidence, and how they would like their doctors to communicate about evidence, with a consideration of what these findings mean for shared decision-making.
- Collaborative focus groups with patients and physicians which defined physician behaviors and patient/parent behaviors that facilitate shared decision-making⁵
- A survey of parents to build an understanding of how they make decisions about whether to use alternative and complementary medicine, including whether they make decisions

with their children's pediatricians. This survey was developed collaboratively with parents, and a focus group of parents assisted with interpretation of the data.⁶

The recent report from the Institute of Medicine, *When Children Die*,² emphasized the importance of developing ways to measure quality of life of children and caregivers, and of finding ways to develop genuine shared decision-making between parents and physicians when creating programs that will better meet the needs of children with life-threatening and advanced illness and their families. The quality of life survey has the potential to become an outcome measurement tool for this population, and developing strategies for shared decision-making is essential to providing care for these children and their families. Therefore, these preliminary studies will form a useful and relevant foundation for the work of this project.

Research Design and Methods

Goal 1: Expand the needs assessments of family members and providers to include additional off-site locations. Modify the needs assessment template developed from NCA and Keesler Air Force Base findings based on experiences at the additional sites.

Activity: needs assessment at San Diego, Madigan and Ft. Leavenworth

Method: case studies with focus groups, interviews, surveys, and analysis of the MHS

Deliverables: report of parent focus groups and interviews; report of health care provider focus groups and interviews, case study reports for San Diego, Madigan and Ft. Leavenworth; integrated case study report; report of the MHS analysis; modified needs assessment template; journal article describing the needs assessment

Study Design

Dr. Hanson and Dr. Randall will conduct a needs assessment of children with life-threatening illnesses and their families who are MHS beneficiaries, using data gathered from families and health care providers at 3 additional military medical centers/clinics (the Madigan Army Medical Center, the Naval Medical Center, San Diego and the Munson Army Medical Clinic at Ft. Leavenworth, Kansas). The data will be summarized as case studies of each of these 3 sites,⁷ and integrated with the Phase I case study information from the National Capital Area (NCA) and the Keesler Air Force Base. Through the Department of Pediatrics and the Department of Family Medicine at USUHS, the researchers have contacts with residency program directors, clerkship site directors, and physicians at these sites. In addition, the researchers have discussed this proposal with the IRB at Keesler Air Force Base Medical Center, a developmental pediatrician at Madigan Army Medical Center, and the Exceptional Family Member Program director at Ft. Leavenworth. All are willing to assist with the project at those sites.

The inclusion of these sites will assure representative information reflecting the military population, as the sites represent major medical centers of the Army, Navy and Air Force and a small installation far from a major military medical center. Children with complex medical needs at Ft. Leavenworth, Kansas receive care at 5 large civilian hospitals in that region.

At each of the 5 sites, the following data collection strategies will be employed to gather information about the needs of children and families, the services available to address those needs, and access and barriers to available services:

- Conducting focus groups and/or interviews of parents of children with life-threatening (both newly diagnosed and advanced) illnesses, or parents of children who have died in the previous two years.
- Conducting focus groups and interviews with pediatricians, pediatric residents, family medicine physicians and residents, and other health care providers that provide care for children with life-threatening illnesses.

- Assembling TRICARE data for the catchment areas represented by the 5 sites, from the TRICARE Management Activity. When possible, more detailed information will be requested from military lead agents and TRICARE contractors, including records of case management for a sample population

Appendix 4 contains a tentative schematic diagram of care for children with life-threatening illnesses and their families. The diagram includes curative care, palliative care during all phases of disease, and a full array of support services, from the time of diagnosis through the time of bereavement. This model will guide the areas that will be explored with families and health care providers in the case studies, and will be modified after consultation with parents. This tentative model was adapted from Feudtner et al.¹⁰ and Hutton et al.¹¹

Sampling strategy

In collaboration with Dr. Naulty, the Maryland Coordinating Center (MCC), and Children's Hospice International (CHI), a sampling strategy will be developed. The following references are available to guide the development of the sampling strategy.

- End-of-Life Survey developed by the Foundation for Accountability (FACCT)⁸ (see Appendix 1).
- Feudtner, C, Hays, RM, et al.¹²
- Reports from PACC projects funded by Congress to work within Medicaid to provide pediatric hospice services in the states.
- CHI's experience with other pediatric hospice projects
- ICF codes.^{13,14}

Advisory group of parents in the National Capital Area

An advisory group of research collaborators will be developed from a group of parents of children who have had, currently are ill with, or have died from chronic life-threatening illness. This group of parents, initially drawn from a group previously assembled under another project, will participate frequently in the work of Phase II by helping adapt a quality of life survey for caregivers, reviewing focus group and interview questions for parents and health care providers, assisting in interpretation of case study data, developing models, developing a program evaluation tool, and editing reports, with an eye toward whether data accurately reflect their experiences^{15,16}. As the mCARE project proceeds, some parents who participate in needs assessment focus groups and interviews may also be invited to join the advisory group.

Collaboration with Family Medicine

While the specialized medical care required by children with life-threatening and advanced illnesses will most often be provided by pediatric subspecialists, these children are often first identified through their primary care physicians in Pediatrics or Family Medicine. Other children in the family will most likely receive care from pediatricians or family medicine physicians, and parents of these children will very likely continue to receive their own care from the family practitioners from whom they were receiving care at the time of their children's diagnoses. Therefore, in order to obtain a thorough understanding of referral pathways for children and the needs of families for health care and support, it is important for the needs assessment to include family physicians as well as pediatricians in focus groups and interviews. While this partnership was not developed in the Phase I proposal of this project, it is important to establish it now.

The Principal Investigator will ensure that family medicine residents and physicians are involved in needs assessment focus groups and/or interviews at all study sites. The Department of Family Medicine at USUHS will assist with this through existing contacts with family physicians at different study sites, and

the faculty will review focus group and interview plans to recommend questions from the family medicine perspective. In addition, the Department of Family Medicine is developing a National Capital Area research consortium with which the Principal Investigator can discuss study plans and issues that emerge during the project.

Focus group and interview plans

The following surveys are available to inform the development of questions and data collection strategies for focus groups and interviews, with guidance from the advisory group:

- The End-of-Life Survey developed by the Foundation for Accountability (FACCT)⁸ (Appendix 1) (integrated in questions for focus groups and interviews, with guidance from an advisory group of parents).
- The Quality of Life of Caregivers of Children with Special Health Care Needs survey developed by Dr. Randall and Dr. Hanson³ (Appendix 2) (integrated in questions for focus groups and interviews, with guidance from an advisory group of parents).
- The Medical Home Assessment Questionnaires and the Medical Home Index (family and provider versions),⁹ which are available from the American Academy of Pediatrics website (see Appendix 3)

During Phase I of the project, interview and focus group questions will be written in collaboration with the parents in the advisory group. After experience with the focus group and interview guides at the first study sites, the researchers will modify the questions (if necessary) for use at subsequent sites.

Adapted quality of life survey for caregivers

Dr. Randall, Dr. Hanson, and a group of parents of children with special needs have developed a survey of the quality of life of caregivers of children with special needs (Appendix 2). The survey has been tested statistically and is psychometrically sound. However, it was developed for use with parents of children with a wide variety of special needs, and requires adaptation for use with parents of children with life-threatening and advanced illness. Dr. Hanson and Dr. Randall will convene the advisory group of parents (described above) to review the survey and recommend changes to wording and/or additional items to address the needs of this group of parents. Collaborating with the advisory group to identify other domains to address in the survey will ensure face validity of the adapted survey, since the parents in this group have had experiences similar to those that the survey will target. When the adapted survey is complete, the questions will be integrated into focus groups and interviews. It will also provide a quality assessment tool for use when planning evaluation of components of the model program that will be developed by the team of mCARE partners.

Parent focus groups and interviews

Parent focus groups and interviews will address the following broad topics: (1) how parents define the needs of children and families when a child has a life-threatening illness; (2) the experience of children and families with the MHS (direct care system and TRICARE) in meeting those needs; (3) the experience of children and families in finding and using services in their communities (both military and civilian communities); (4) education and information necessary to enable them to find and access the health care and services that they need, and (5) the degree to which the children's care has been coordinated and what the mechanisms of coordination have been. Focus groups and interviews will be audiotaped and transcribed. Parents will be offered both formats (focus groups and interviews), since the medical needs of their children may be complicated, and one format or the other may be more accessible for them. They may be asked to complete a survey in the context of a focus group or interview (see Appendices 1, 2 and 3).

Health care provider focus groups and interviews

Health care provider focus groups will be held at each Military Treatment Facility (MTF) to discuss three broad topics: (1) how residents, pediatricians, family medicine physicians and other health care providers define the needs of the children with life-threatening conditions and their families for whom they provide care; (2) participants' experiences with the MHS (direct care system and TRICARE) in meeting those needs; (3) education and information necessary to help them provide comprehensive care in a Medical Home model for children with life-threatening illnesses and their families (mCARE).¹⁷ Interns/residents and staff physicians will participate in separate focus groups. Focus groups will be audiotaped and transcribed. Individual interviews may be conducted with health care providers who have specific knowledge and experience working with the families of children with life-threatening conditions. They may also be asked to complete a written survey regarding providing care for children with life-threatening illnesses within a Medical Home model⁹ (see Appendix 3).

Military Health System Analysis

The Military Health System (MHS) analysis will include analysis of the military direct care system capability and capacity and the TRICARE benefit manual (available at <http://www.tricare.osd.mil/tricaremanuals/>). The following sources will be used to derive information:

- The TRICARE benefit manual.
- TRICARE reimbursement rates.
- Pending legislation for TRICARE.
- Policy makers at the TRICARE Management Activity.
- Case managers at lead agencies.
- Case managers at MTFs.
- Contract language.
- Contractor representatives.
- Medicare/Medicaid benefits and reimbursement rates.
- Pending legislation for Medicare/Medicaid.

From these sources, the researchers will derive descriptions of the following aspects of the MHS:

- Relevant covered care and services
- Definitions applicable to children with life-threatening illnesses
- History of care and services provided for children with life-threatening illnesses through the military direct care system and TRICARE (case examples, aggregate CPT and ICD-9 codes)
- Historical costs for this population of children
- Pending changes that may affect access to care and services for this population
- Policy makers', Lead Agents' and Contractors' interpretation of relevant benefits
- Explicitly-excluded care and services needed by children with life-threatening illnesses
- Current reimbursement rates for care and services through TRICARE and Medicaid.

Mapping

The needs assessment will delineate the needs of children and families from the perspectives of parents and health care providers, as well as the services these families use and the ease with which they can access those services. The MHS analysis will identify relevant aspects of the TRICARE benefit and the MHS. The Maryland Coordinating Center (MCC) will identify relevant resources in the community. Ultimately, the researchers will compare the needs of children and families with resources available through the MHS and civilian and military communities.

In the National Capital Area (NCA), it will be possible to create maps of the resources accessed, resources needed but not available, and resources available but not adequately accessed by the families in the study. There is software available to create geographic maps of families and available resources,

and faculty members in the Department of Preventive Medicine and Biometrics at USUHS have experience using this software. The researchers will create maps with this software to portray and family locations in the NCA, using the results of the needs assessment and the community resource guide from the MCC. If this mapping produces helpful displays for analysis and planning, similar mapping will be done at the other study sites, and a plan for mapping will be developed as part of the needs assessment template

Timeline

A task schedule for the above activities appears in Appendix 5.

Recruitment of Parents

Eligible parents will be identified by Military Healthcare System staff at each study site, including pediatricians, family medicine physicians, residents, nurses, and care coordinators. This identification will be based on knowledge of children's conditions known to the staff in their day-to-day duties in providing medical care and/or case management services. No new knowledge about children or parents will be learned by the staff identifying parents to the researchers in this study. Children may be enrolled in TRICARE Prime and/or using TRICARE Extra, Standard, Medicaid, Medicare, other government programs or health insurance

MHS staff will forward the name, phone number, and brief description of each child's condition to Dr. Naulty (Principal Investigator at Walter Reed (WRAMC)), Dr. Hanson (Principal Investigator at the Uniformed Services University (USUHS)) or Dr. Randall (Associate Investigator at the Uniformed Services University (USUHS)). One of them will call parents using the attached phone script (see Appendix 8) for the purpose of recruiting parents to the study. Parents will have the option of participating in an individual interview in their own home, a focus group, or both. Focus groups will take place at USUHS or WRAMC in the NCA or the military treatment facility at another site. Focus group participants will receive a \$50 subject fee. Parents will receive a \$30 subject fee paid for home interviews. Active duty parents must be on leave or off-duty hours to receive a subject fee. Military personnel stationed at USUHS cannot be paid. Written informed consent will be obtained from each parent before the home interview or focus group begins. See Appendix 7 for the text of the consent forms. Interviews and focus groups will be audiotaped with permission of the parents.

Fliers (see Appendix 9) will also be distributed in the clinics where such patients receive care within the MHS. Parents may self-identify through the information and contact phone number(s) provided in the flier or through word-of-mouth from other families.

Data Analysis Plan

Data analysis will include both qualitative and quantitative analysis methods within a case study design, in which the cases studies are the 5 identified military treatment sites. For each study site, data analysis will include the following components:

Qualitative analysis

1. Parent focus groups and interviews
 - a. Gather field notes
 - b. Audiotape and transcribe focus group content
 - c. Audiotape and transcribe parent interviews
 - d. Identify themes using HyperResearch¹⁸ qualitative data analysis software. Identify themes in these areas:
 - i. Child and family needs
 - ii. Resources used
 - iii. Resources needed but not accessible, available or adequate, and why

2. Health care provider focus groups and interviews
 - a. Gather field notes
 - b. Audiotape and transcribe focus group content
 - c. Record interview notes
 - d. Identify themes using HyperResearch ¹⁸ qualitative data analysis software. Identify themes in these areas:
 - i. Child and family needs
 - ii. Resources used
 - iii. Resources needed but not accessible, available or adequate, and why

Quantitative analysis

1. Summarize survey data
 - a. Gather selected End-of-life survey (FACCT)⁸ data during focus groups and parent interviews
 - b. Gather selected Quality of Life of Caregivers of Children with Special Health Care Needs survey³ data during focus groups and parent interviews
 - c. Gather selected Medical Home Assessment surveys⁹ data during focus groups and interviews
 - d. Tabulate data and portray graphically with Microsoft Excel ¹⁹
2. Summarize resources used as reflected by available TRICARE data
 - a. Obtain available data from the TRICARE Lead Agent and contractor
 - b. Tabulate data and portray graphically with Microsoft Excel ¹⁹

Summative analysis

1. Summarize qualitative and quantitative parent data in these areas:
 - a. Child and family needs
 - b. Resources used
 - c. Resources needed but not accessible, available or adequate, and why
2. Summarize qualitative and quantitative health care provider data in these areas:
 - a. Child and family needs
 - b. Resources used
 - c. Resources needed but not accessible, available or adequate, and why
3. Convene advisory focus groups in the National Capital Area to interpret data summaries
4. Develop concept maps with Decision Explorer ²⁰ software
5. Develop a needs assessment template
 - a. Compile focus group and interview questions, surveys used, concept maps and any additional data collection strategies developed during the case study at site 1
 - b. Apply the needs assessment template from site 1 at sites 2, 3, 4 and 5; modify as necessary
 - c. Summarize needs assessment strategies used at all sites
6. Write a narrative summary for each site

Data analysis references

The overall approach to data analysis is described in by Pope and Ziebland ²¹ and in volumes 5 of The Ethnographer's Toolkit, *Analyzing and Interpreting Ethnographic Data*. ²²

Expected Results

Focus group and interview plans

Interview and focus group questions will be written in collaboration with the parents in the advisory group. After experience with the focus group and interview guides at the first study sites, the researchers will modify the questions (if necessary) for use at subsequent sites.

Needs assessment template

A needs assessment template will be developed in the NCA, and then modified for use at each subsequent study site. The template will include plans for focus groups and interviews with parents and health care providers, relevant surveys, a list of data to request from TRICARE lead agents and contractors, and a list of other data to gather in a community when assessing care and services for children with life-threatening illnesses and their families. When the Maryland Coordinating Center completes a guide to community resources, this will be incorporated in the needs assessment template as well. After a model of care is developed in this project, the needs assessment can be used when implementing the program in other communities where the Military Health System provides care and services.

Adapted quality of life survey for caregivers

One important product of this research will be an adapted survey to measure the quality of life of caregivers of children with life-threatening or advanced illness. Once complete, this survey will guide data collection during this project. It will also provide a quality assessment tool for use when planning evaluation of components of the model program that will be developed by the team of mCARE partners, as well as contributing to the larger literature about developing and assessing care and services for this group of children and their families.

Report of parent focus groups and interviews

This report will focus on these four facets of the needs assessment.

- Child and family needs as described by parents
- Resources families use in the MHS and community
- Resources needed but not accessible, available or adequate, and the barriers families experience when trying to obtain these resources.
- Families' needs for information and education regarding these needs, resources and gaps in services.

Report of health care provider focus groups and interviews

This report will focus on three facets of the needs assessment

- How residents, pediatricians (both general pediatricians and subspecialists) and family medicine physicians, and other health care providers define the needs of the children and families for whom they provide care.
- Their experiences with the MHS (direct care and TRICARE benefit) and community services in meeting those needs
- How residents, pediatricians, family medicine physicians, and other health care providers describe gaps in needed care and services.
- Education necessary to help physicians and other health care providers provide care in a Medical Home model for children with life-threatening illnesses and their families.

Case study reports

The researchers will produce a case study report for each study site (NCA, Keesler, Madigan, San Diego and Ft. Leavenworth), as well as an integrated report that will summarize the findings across sites. Each report will describe the needs of children and families, the resources used, and the resources needed but not accessible, available or adequate, incorporating the perspectives of families and health care providers. The data delineated above will be used to map the networks of services and informal social support used by families in each geographic area, using concept maps and geographic maps as appropriate to show the locations of families and the services they access.²³ Gaps in services and support will be delineated, with policy recommendations for the military health system to address these gaps. The reports will also summarize relevant needs of families, physicians and other health care providers for education and information about care and services and how to access them.

Military Health System Analysis report

The MHS analysis report will contain:

- A description of the benefits and services routinely available to families and their children.
- A description of the benefits and services that are either not easily accessible or are not authorized. This description may include:
 - The legislative history of the omission of benefit authorization from the TRICARE manual.
 - A description of how the TRICARE contract language prevents families from accessing the benefit.
 - A description of how the TRICARE definitions prevent families from accessing the benefit.
- Alternatives for ensuring the families and children receive the necessary medical benefits will be provided. This may include new legislative language, new definitions, or new procedures for contractors or case managers/care coordinators/primary care providers.
- A description of implications for eligibility criteria for services within the TRICARE benefit

Manuscripts for peer-reviewed journals

The needs assessment will also lead to research reports that will be submitted as manuscripts to peer-reviewed journals in the health care literature.

Human Subjects Protections

Phase I of this research has been approved by the Institutional Review Board at the Uniformed Services University (see Appendix 10). Any additions to the research protocol that appear in this proposal will be submitted to the USUHS IRB as a modification. The protocol will be submitted for required IRB approval at Walter Reed Army Medical Center, Malcolm Grow Air Force Medical Center and the National Naval Medical Center in the NCA, as well as to Ft. Detrick. The protocol will also be submitted as required to IRBs for Keesler Air Force Base Medical Center, Madigan Army Medical Center, the Naval Medical Center, San Diego, and Ft. Leavenworth.

Two categories of human subjects will be involved in the needs assessment:

1. parents of children with life-threatening illnesses and
2. health care providers who provide services for these children and their families

When collecting data, the researchers will not actively seek sensitive information (e.g., drug and alcohol use, sexual practices, child or spousal abuse, or other information that could be criminal or damaging to one's financial or social standing, employability, insurability, or psychological well-being) for either group of participants. However, parents may volunteer sensitive information during interviews or

focus groups. The current version of the quality of life of caregivers survey contains questions with references to drug and alcohol use and to stress that might be expressed in a way that could harm a child. These topics are not the focus of the survey, nor will they be the focus of the interviews and focus groups. Parents will not be asked directly about these topics.

Parents will be involved in two ways, as participants in the needs assessment and as research collaborators in an advisory group. The advisory group will consist of 8-10 parents in the National Capital Area (NCA). They will be parents of children with life-threatening illnesses or of children who have died. Parents in the advisory group will have had some experience participating in research and/or medical education activities, either in the mCARE project or in other research and education projects with the Principal Investigator and Co-Investigator.

In addition to the advisory group, the number of participants in the needs assessment will be parents from approximately 50 families and approximately 40 healthcare providers, apportioned among the following study activities. The needs assessment will involve approximately half of the participants in each of the two phases of the study. Phase I has already been funded. Phase II is described in this proposal

- Interviews: 10 families in the National Capital Area; 3 families at each of 3 other sites with major military medical centers; 1 family at 1 small installation with limited military medical resources (20 total) (Note: there could be 1-4 parents/step-parents per family).
- Surveys. 50 families (total, includes any TRICARE beneficiary family in any geographic location) (families completing survey may also participate in an interview or focus group).
- Focus groups with parents. up to 25 families total at all sites if focus groups are needed in addition to in-home interviews.
- Focus groups and interviews with residents, attending physicians, and other health care providers: 40 healthcare providers total.

Parents of children with life-threatening (both newly diagnosed and advanced) illnesses are being studied to determine the needs of these children and their families in the event of such an illness and to determine how well these needs are met by existing military medical, TRICARE, and community resources. The system of services available to military families with this circumstance will be analyzed for availability, accessibility and effectiveness, resulting in recommendations for changes to the TRICARE benefit and/or mechanisms by which families access TRICARE, military, and community resources. Participants will be invited to join the research on the basis of whether they are parents of children with life-threatening illnesses or healthcare providers who provide services to children of this description. Families will be TRICARE beneficiaries, active duty or retired. Healthcare providers will be those who provide services to TRICARE beneficiaries.

The study participants will be adults (parents of children with life-threatening illnesses, parents of children who have died within the previous 2 years and residents, staff physicians, and other healthcare providers such as nurse and care coordinators). The study will include both male and female participants. Their physical and psychiatric conditions will not be identified. The researchers will seek participants from diverse racial and ethnic backgrounds.

For recruiting families in the National Capital Area, two contacts have been identified: Dr. Cheryl Naulty, Medical Director, Exceptional Family Member Program/Educational and Developmental Intervention Services, WRAMC/NAMC is Principal Investigator of the larger project of which this protocol is a part. Dr. Naulty has privileges at both Walter Reed Army Medical Center (WRAMC) and the National Naval Medical Center (NNMC). Deborah Wills, R.N., is a nurse in Pediatric Hematology/Oncology at WRAMC who works with families with children with life-threatening illnesses and will be one of the staff members working on this project. Dr. Naulty and Ms. Wills will explain the study to parents and healthcare providers, present the consent forms, and ask if they would like to participate in the study. They will also ask other healthcare providers to invite families to participate. At each other study site, we will identify a physician or nurse to serve as a contact. Physicians and nurses will invite families to participate. Families

who are interested may contact Dr. Naulty, Ms. Wills, or Dr. Hanson (the PI for this needs assessment), or sign a consent form and agree to be contacted by one of us.

At the other sites with major military treatment facilities (Madigan, San Diego and Keesler), the principal investigator will contact the site directors for the USUHS Pediatric and Family Medicine Clerkships, to establish contacts with the local IRB and residency programs and other necessary contacts to accomplish the project.

Possible risks and procedures to minimize them

For healthcare providers, there are no anticipated individual health or injury risks associated with this study. There are no anticipated risks to psychological health, although they may experience feelings of frustration, anger and sadness as they talk about children they have cared for or are caring for at the time. They will be free to decline to answer any questions. They will also be free to withdraw from the study at any time. Comments made in a focus group will be heard by others in the focus group, some of whom may be their colleagues. Focus group guidelines will specify that comments made in the group are confidential. Staff physicians and residents will participate in separate focus groups, so residents will feel free to share their observations and concerns openly. Research staff will be trained to conduct interviews and focus groups with sensitivity and will complete training in the ethics of doing research with human participants. Consent forms will provide information about how to access mental health services through TRICARE and also how to get a referral to a provider through the American Psychological Association, should such services be needed. Confidentiality of the healthcare providers' information will be maintained. Any identifying information will be stored in locked cabinets in the offices of the Principal Investigator on the premises of USUHS. Access to information that could identify them will be restricted to members of the research team. The names of healthcare providers who participate will not appear in any published papers or presentations related to this study without their express written consent, and then only to acknowledge their contribution to the study.

For parents, there are no anticipated individual health or injury risks associated with this study. There are anticipated risks to psychological health. They quite likely will experience feelings of sadness, unhappiness, anger and/or frustration as a result of discussing their children's condition or death. They may experience these same feelings as they discuss their experiences in looking for or finding resources and services. They are free to decline to answer any questions. They are also free to stop participating in the study at any time. Research staff will be trained to conduct interviews and focus groups with sensitivity and will complete training in the ethics of doing research with human participants. Consent forms will provide information about how to access mental health services through TRICARE and also how to get a referral to a provider through the American Psychological Association, should such services be needed. Confidentiality of the parents' information will be maintained. Any identifying information will be stored in locked cabinets in the offices of the Principal Investigator on the premises of USUHS. Access to information that could identify them will be restricted to members of the research team. The names of parents who participate will not appear in any published papers or presentations related to this study without their express written consent, and then only to acknowledge their contribution to the study.

Confidentiality of Data

Confidentiality of information provided by parents and health care providers will be maintained. Their names will not appear in any published paper or presentation related to this study without their expressed written consent, and then only to acknowledge their contribution to the study. Information that can be linked to participants will be stored in locked cabinets in the offices of the Principal Investigator on the premises of USUHS. Electronic data files with information about them will be password protected and access to these files will be restricted to members of the study staff. The computer that stores files with identifying information will not be connected to the internet, a network, or a phone line.

We will contact the TRICARE Management Activity and Lead Agents for TRICARE regions to request data reflecting use of services covered by the TRICARE benefit for patients who fit the criteria established in the project to determine eligibility as "a child with a life-threatening illness." No patient identifiers will be needed.

For survey, interview, and focus group data, the participants will be identifiable. The following procedures will be taken to assure confidentiality of the data:

- Surveys. Since the surveys will be used as a tool during interviews and focus groups as part of a comprehensive case study research methodology, the identities of parents will be known and recorded when they complete the survey. Identifiers will not be associated with survey data when it is analyzed or reported.
- Interviews. Since interviews will be conducted as part of a comprehensive case study research methodology, the identities of families and health care providers will be known and recorded at the time of the interviews. Interviews will be tape recorded and transcribed. Identifiers will not be associated with interview data when it is analyzed or reported.
- Focus groups with parents: Since focus groups will be conducted as part of a comprehensive case study research methodology, the identities of families will be known and recorded at the time of the groups. Interviews will be tape recorded and transcribed. Identifiers will not be associated with interview data when it is analyzed or reported.
- Focus groups of residents, attending physicians, and other healthcare providers: We will not associate identifiers with data collected in focus groups or interviews with healthcare providers. We will describe the disciplines of healthcare providers in the groups.

Application of Research Results

Goal 2: Define the eligibility criteria for the population of children to be served.

Activity: participate in mCARE workgroup to define eligibility criteria

Method: review literature; review TRICARE benefit, policy and legislative history; consult with experts

Deliverable: contribution to workgroup, written summary of information reviewed

USUHS personnel will participate in a workgroup with other mCARE partners to define eligibility for an mCARE model program and eligibility for receipt of pediatric hospice and related services as part of the TRICARE benefit. Preparation for the workgroup will involve reviewing relevant literature and reviewing the TRICARE benefit, policy and legislative history. The analysis of the MHS described in the needs assessment will inform the definition of eligibility. Eligibility criteria will define the threshold of severity of illness or diagnosis necessary to receive mCARE services. The following sources will be reviewed for definitions that can inform these criteria:

- CHI PACC programs in the states.
- Hospice/palliative care programs based in hospitals that serve children (such as those at Dana Farber Cancer Institute in Boston and Johns Hopkins in Baltimore)
- Quality of life indicators such as those in the End-of-Life Survey developed by the Foundation for Accountability (FACCT) ⁸ (see Appendix 1).
- Articles in the peer-reviewed literature, such as Feudtner et al.¹² and the American Academy of Pediatrics website on the Medical Home.⁹
- Published literature demonstrating ways of defining the potential population eligible for care by DRGs, numbers of hospitalizations/year, codes for diagnoses and severity, and estimates of burden of care on families.
- Examples of specific wording found in TRICARE programs (e.g., ECHO and PFPWD).

- TRICARE experience with the IMPC-PEC program (case management of expensive cases).
- Existing community-based care coordination centers that have experience with children who qualify for the Medicaid Waiver, such as the Maryland Coordinating Center.
- Criteria for the Medicaid Waiver.
- Recommendations in the the Institute of Medicine Report.²
- ICF codes that consider functional abilities, which are under development by Rune Smeonsson and colleagues.^{13,14}

Goal 3: Develop a framework for datasets to support the new model design.

Activity: develop datasets for the proposed model

Method: participate in mCARE team meetings

Deliverable: meeting participation

USUHS personnel will participate in mCARE team planning meetings where a framework for datasets will be discussed, contributing insights from the needs assessment and MHS analysis to development of a framework and descriptors of fields for datasets needed to coordinate information about children and families and relevant care and services in the model program.

Goal 4: Develop a plan for a flexible website for multiple user groups that houses the various datasets discussed in goal 3.

Activity: develop a plan for a flexible website for mCARE

Method: participate in mCARE team meetings

Deliverable: meeting participation, advisory group perspectives

USUHS researchers will participate in mCARE team planning meetings, contributing information from the needs assessment and MHS analysis to discussions about a website that will support the needs of the mCARE program. The advisory group of parents will be available to review website concepts, terminology and presentation as needed.

Goal 5: Develop a plan for the education of families.

Activity: develop a plan to educate families of children with life-threatening illnesses and MHS health care providers

Method: critique case studies, consult with advisory group of families, work with mCARE partners

Deliverable: draft of a plan for education of families in the mCARE model

The case study reports and other results of the needs assessment will provide information needed to develop an approach to education for families. Education will encompass MHS and civilian community resources and how to access them, building partnerships with health care providers and participating in shared decision-making. USUHS researchers will develop implications of the needs assessment for education of families and draft a plan for education. The plan will be discussed, revised and prepared for implementation in collaboration with other mCARE partners. The advisory group will be available to review and comment on draft plans. Children's Hospice International will develop curricula for healthcare providers, and the needs assessment results will inform the development of these educational materials.

Goal 6: Design new model of care with cost projections in preparation for implementation and cost analysis.

Goal 7: Develop implementation strategies for the new model design.

Activity: participate in development of the mCARE model of care and implementation strategies

Method: participate in mCARE team planning meetings and work groups, applying the results of the needs assessment

Deliverable: results of needs assessment and the associated tools and reports, meeting participation

USUHS researchers will participate with mCARE partners in team planning meetings and workgroups to develop a proposed model of care for children with life-threatening illnesses and their families. The needs assessment reports and MHS analysis will provide crucial information to guide the development of this model.

Goal 8: Design a methodology and conduct a pilot study to evaluate certain identified components of the new model design, e.g. respite care, care coordination. The evaluation should address strategies for implementation of these components.

Activity: program evaluation of pilot components of the proposed mCARE model

Method: work with mCARE partners to design program evaluation of components of the new model

Deliverable: survey of the quality of life of caregivers, adapted for parents of children with life-threatening illnesses, program evaluation design (developed collaboratively)

In collaboration with the advisory group of parents (described in the needs assessment plans), project researchers at USUHS will adapt a survey to measure quality of life of caregivers of children with special needs to families with children with life-threatening illnesses. See Appendix 2 for the current version of this survey. The IOM report *When Children Die*² cites quality of life of both children and caregivers as a key outcome measure of pediatric hospice programs, but the field is in need of valid ways to measure this dimension.

With mCARE partners, the USUHS researchers will participate in planning and implementing evaluation of components of the proposed mCARE model. The quality of life of caregivers survey will provide a valuable resource for measuring outcomes. Two components recommended for early evaluation are respite care and care coordination. The MCC has extensive experience implementing respite care (the Take a Break program) and care coordination, and can provide clear definitions and descriptions of these services, as well as existing data, to guide the development of solid program evaluation. The mCARE needs assessment will also provide a clear understanding of the outcome variables that are important to both families and health care providers. The advisory group will be available to review plans, data and interpretations from a parent perspective.

The proposed model will also comprise education of physicians and other health care providers. The needs assessment—particularly the report of focus groups and interviews with health care providers, will provide essential insight regarding the educational needs of health care providers in the MHS. The USUHS researchers will participate in plans to modify, implement and evaluate educational approaches for health care providers in the MHS.

Investigators' Qualifications

Please see the attached biographical sketches (Appendix 6).

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APPENDIX 3

Objectives 1 & 2:

mCARE Needs Assessment, USUHS Year 1 Activities

Dec 2003 Full IRB committee review, USUHS, FY03 protocol.

Jan 2004 Received conditional approval letter from USUHS IRB

Mar 2004 Hired Melissa Bellin as mCARE Research Associate.

April 2004 Submitted required changes to USUHS IRB (response to conditional letter of approval)

May 2004 May 20, 2004—received unconditional letter of approval and approved consent documents from USUHS IRB for FY03 protocol, with an error regarding compensation for active duty parent participants.
Conferred with General Counsel and IRB office at USUHS regarding above error.
May 27, 2004—received corrected unconditional letter of approval from USUHS IRB, with corrected copy of parents' informed consent document.
May 28, 2004—submitted proposal for FY04 appropriation; added to plan for the needs assessment and submitted this protocol as a modification to the USUHS IRB.

June 2004 The USUHS IRB reviewed the FY04 needs assessment protocol and consolidated it with the FY03 protocol. We now have one USUHS IRB-approved protocol.
June 4, 2004—submitted protocol and supporting documentation to HSRRB office at Ft Detrick (Ft. Detrick had not identified this as a study that involves human participants, which should have happened when the proposal was submitted to Ft. Detrick in July 2003).
June 8, 2004—submitted protocol to DCI at WRAMC

July 2004 July 1, 2004—received approval for modification #1, which incorporated the additional activities, clarifying details, and modified timeline of the FY04 needs assessment proposal.
July 1, 2004—submitted protocol to NNMC.
July 12, 2004—full review of protocol by Malcolm Grow IRB.
Met with Clinical Investigation Committee at WRAMC, provided response to their review.
July 20, 2004—received approval for modification #2 from USUHS IRB (added surveys in appendices, inadvertently omitted from 7/1/04 protocol. New consolidated protocol dated 7/20/04)

July- Aug 2004 Had discussion with DSRRB office at Ft. Detrick. They told us that USUHS would be recognized as the IRB of record, and Ft. Detrick would not do a separate review. Documentation of this understanding was to be provided by the end of Aug 2004

Aug 2004 Received letter of approval from Malcolm Grow IRB.
Aug 24, 2004—received approval for modification #3 from USUHS IRB, health care recruitment materials.

Late Aug 2004 Informed that HSRRB office at Ft. Detrick would, after all, have to do a “secondary review” of the protocol and we would have to coordinate a revised version of the protocol between USUHS & Ft. Detrick.

Aug Sept 2004 Prepared and submitted revised documents to WRAMC HUC.

Sept 2004 Prepared peer review response for FY04 proposal (needs assessment piece)

Oct 2004 Early Oct 2004—received review from NNMC IRB (from an individual reviewer); began to prepare response.
Received Ft. Detrick preview of protocol
Full review by WRAMC IRB.
Oct 15, 2004—received approval for modification #4 from USUHS IRB generic template and site specific health care provider recruitment materials.

Nov 2004 Submitted updated letters of approval, letters of support and health care provider recruitment materials to Malcolm Grow IRB.
Attended project team meetings throughout the year and provided input regarding overall project objectives.

APPENDIX 4

BENEFITS AVAILABLE IN TRICARE/CHAMPUS FOR CHILDREN WITH LIFE THREATENING ILLNESSES AND THEIR FAMILIES

Respite Care

BENEFIT	CITATION	DESCRIPTION OF BENEFIT	COMMENTS	GAP
Respite care	TRICARE Extended Care Health Option (ECHO). Final Rule/FR Vol 69, No 144, Jul 28, 2004	(c)(7) Respite care ECHO beneficiaries are eligible for 16 hours of respite care per month in any month during which the qualified beneficiary otherwise receives an ECHO benefit(s). Respite care is defined in Sec. 199.2. Respite care services will be provided by a TRICARE-authorized home health agency and will be designed to provide health care services for the covered beneficiary, and not baby-sitting or child-care services for other members of the family. The benefit will not be cumulative, that is, any respite care hours not used in one month will not be carried over or banked for use on another occasion.	<p>Pending signature and contract modifications.</p> <p>Part 199.2 Definitions (b) Specific definitions.</p> <p><u>Mental retardation</u> – A diagnosis of moderate or severe mental retardation made in accordance with the criteria of the current edition of the "Diagnostic and Statistical Manual of Mental Disorders" published by the American Psychiatric Association</p> <p><u>Serious physical disability</u> – Any physiological disorder or condition or anatomical loss affecting one or more body systems which has lasted, or with reasonable certainty is expected to last, for minimum period of 12 contiguous months, and which precludes the person with the disorder, condition or anatomical loss from unaided performance of at least one Major Life Activity as defined in this section.</p> <p><u>Extraordinary condition</u> A complex clinical condition, which resulted, or is expected to result, in extraordinary TRICARE/CHAMPUS costs or utilization, based on thresholds established by the Director, OCHAMPUS, or designee.</p> <p><u>Extraordinary physical or psychological condition</u> A complex physical or psychological clinical condition of such severity which results in the beneficiary being homebound as defined in this section.</p> <p><u>Homebound</u> – A beneficiary's condition is such that there exists a normal inability to leave home and, consequently, leaving home would require considerable and taxing effort...Absences...for the purpose of attending an educational program...shall not negate the beneficiary's homebound status</p> <p><u>Major Life Activity</u> – Breathing, cognition, hearing, seeing, and age appropriate ability essential to bathing, eating, grooming, speaking, stair use, toilet use, transferring, and walking.</p> <p><u>Respite care</u> – Respite care is short-term care for a patient in order to provide rest and change for those who have been caring for the patient at home, usually the patient's family.</p>	Available only for TRICARE-eligible family members of active duty service members

		Government cost-share maximum monthly benefit of \$2,500
	Part 199.5 TRICARE Extended Care Health Option (ECHO), Jul 28, 2004 (e)ECHO Home Health Care (EHHC).	<p>(e)(2) EHHC beneficiaries whose plan of care includes frequent interventions by the primary caregiver(s) are eligible for respite care services in lieu of the ECHO general respite care benefit. For the purposes of this section, the term "frequent" means "more than two interventions during the eight-hour period per day that the primary caregiver would normally be sleeping." The services provided...are those that can be performed ...by the average non-medical person...after has been trained by appropriate medical personnel.</p> <p>EHHC beneficiaries in this situation are eligible for a maximum of eight hours per day, 5 days per week, or respite care by a TRICARE-authorized home health agency.</p> <p>(e)(3) EHHC eligibility. Beneficiaries meet all ECHO eligibility requirements and who: (i) are homebound; (ii) require medically necessary skilled services that exceed the level of coverage provided under the Basic Program's home health care benefit; (iv) or require frequent interventions by the primary care giver(s) such that respite care services are necessary to allow primary caregiver(s) the opportunity to rest, and are case managed to include reassessment at least every 90 days and receive services as outlined in a written plan of care; and (vi) receive all home healthcare services from a TRICARE-authorized home health agency as described in Sec 199 6(b)(4)(xv), in the beneficiary's primary residence.</p> <p>(e)(4) EHHC plan of care. A written plan of care is required prior to authorizing ECHO home health care. The plan must include the type, frequency, scope and duration of the care provided and support the professional level of the provider</p>

Home Health Care

<p>Home health care</p> <p>Part 199.5 - TRICARE Extended Care Health Option (ECHO) July 28, 2004</p>	<p>(e)(1) ECHO Home Health Care (EHHC) Home health care. Covered ECHO home health care services are the same as, and provided under the same conditions as those services described in Sec 199.4, except that they are not limited to part-time or intermittent services</p> <p>(f)(3)(n) ECHO home health care. The maximum annual Government cost-share for ECHO home health care, including EHHC respite care may not exceed the local wage-adjusted highest Medicare Resource Utilization Group (RUG-III) category cost for care in a TRICARE-authorized skilled nursing facility</p>	<p>(e)(12)(i)(B)One hour per day of nursing care may be authorized if patient is determined to be receiving custodial care.</p> <p>(e)(21)(1) Home health services. Home health services are covered when furnished by, or under arrangement with, a home health agency (HHA) that participates in the TRICARE</p>	<p>Network inadequate.</p> <p>May be authorized when physician certifies need for home health services, services provided under a plan of care established and</p>
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	<p>program and provides care on a visiting basis in the beneficiary's home. Covered HHA services are the same as those provided under Medicare under section 1861(m) of the Social Security Act. ...Benefit coverage...part-time or intermittent skilled nursing care, physical therapy, speech-language pathology, and occupational therapy, medical social services, part-time or intermittent services of a home health aide, medical supplies, a covered osteoporosis drug, and durable medical equipment, services at hospitals, SNFs or rehabilitation centers</p> <p>approved by a physician, plan of care contains all pertinent diagnoses,...type of services . Beneficiary must need skilled nursing care on an intermittent basis or physical or speech language pathology services, or have a continued need for occupational therapy after the need for skilled nursing care, physical therapy, or speech-language pathology services has ceased... Incorporates the current version of the Outcome and Assessment Information Set (OASIS)</p>
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Custodial Care

<p>Custodial care</p> <p>Part 199.5 – TRICARE Extended Care Health Option (ECHO) July 28, 2004</p>	<p>(e)(1)...Custodial care services, as defined in Sec 199.2, may be provided to the extent such services are provided in conjunction with authorized ECHO home health care services, including the EHC respite care benefit.</p>	<p>Custodial care services may be provided only as specifically set out in ECHO.</p>
<p>Part 199.4 Basic Program Benefits</p>	<p>(e)(12) Custodial care The statute under which CHAMPUS operates specifically excludes custodial care .CHAMPUS benefits are not available for services related to a custodial care case, with the following specific exceptions: (A) Prescription drugs and medicines, medical supplies and durable medical equipment. (B) Nursing services, limited Recognizing that even though the care being received is determined primarily to be custodial, an occasional specific skills nursing service may be required When it is determined such skilled nursing services are needed, benefits may be extended for one hour of nursing care per day.</p>	<p>Home maker services available under Medicaid hospice and in Basic Program hospice.</p>
<p>Home-maker</p>		

		<i>Skilled Nursing Facility</i>
Skilled nursing facility	Part 199.4 – Basic Program	<p>(b)(3)(xiv) Covered services in SNFs are the same as provided under Medicare, except that the Medicare limitation on the number of days of coverage... shall not be applicable under TRICARE.</p> <p>Skilled nursing facility care for each spell of illness shall continue to be provided for as long as necessary and appropriate ... Extended care services... include .nursing care, bed and board, physical or occupational therapy and speech language pathology, medical social services, drugs, supplies, appliances, and equipment.</p>

<i>Prescription Drugs</i>			
Prescription drugs and medicines	Part 199.4 Basic Program Benefits	(d)(vi) Prescription drugs and medicines that by U.S. law require a physician's or other authorized individual professional providers ... in connection with an otherwise covered condition or treatment.	

Dental Care and Oral Surgery

Dental care	Part 199.4 – Basic Program Benefits	(e)(10)Dental care which is medically necessary in the treatment of an otherwise covered medical (not dental) condition, is an integral part of the treatment of such medical condition and is essential to the control of the primary medical condition. list of conditions... (1) Intraoral abscesses with extend beyond the dental alveolus (2) Extraoral abscesses ... (iv) covered oral surgery (A) Excision of tumors and cysts of jaws, cheeks, lips, tongue and roof and floor of mouth... (C) Treatment of facial or oral cancer.
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		<i>Counseling Services</i>	Excluded in hospice care through Basic Program Available in Medicaid hospice program
Bereave-ment care	Part 199.4 - Basic Program	(c)(ix) Treatment of mental disorders...the patient must be diagnosed by a CHAMPUS-authorized mental health professional to be suffering from a mental disorder...in order for treatment of a mental disorder to be medically or psychologically necessary, the patient must, as a result of a diagnosed mental disorder, be experiencing both physical or psychological distress and an impairment in his or her ability to function in appropriate occupational, education, or social roles	
Counseling for child before child's death	Part 199.4 - Basic Program	(ix) Treatment of mental disorders ...the patient must be diagnosed by a CHAMPUS-authorized mental health professional to be suffering from a mental disorder...in order for treatment of a mental disorder to be medically or psychologically necessary, the patient must, as a result of a diagnosed mental disorder, be experiencing both physical or psychological distress and an impairment in his or her ability to function in appropriate occupational, education, or social roles	

Care Management/Care Coordination Services

Care co-ordination	Part 199.5 Extended Care Health Option (e)(4)	EHHC plan of care. A written plan of care is required prior to authorizing ECHO home health care. The plan must include the type, frequency, scope and duration of the care provided and support the professional level of the provider.
	Part 199.4 – Basic Program (e)(19)	Hospice Care requires a care plan
	Part 199.4 – Basic Program (b)(3)(ivx)	Hospitalization in skilled nursing facility requires a care plan.
	Nursing case manage-ment	

<u>Hospice</u>	Part 199.4 – Basic Program	<p>(e)(19) Hospice Care. Hospice care is a program which provides an integrated set of services and supplies designed to care for the terminally ill. This type of care emphasizes palliative care and supportive services, such as pain control and home care, rather than cure-oriented services provided in institutions that are otherwise the primary focus under CHAMPUS. The benefit provides coverage for a humane and sensible approach to care during the last days of life for some terminally ill patients.</p> <p>(1) Benefit coverage. CHAMPUS beneficiaries who are terminally ill (that is, a life expectancy of six months or less if the disease runs its normal course) will be eligible for the following services and supplies in lieu of most other CHAMPUS benefits:</p> <ul style="list-style-type: none"> (A) Physician services. (B) Nursing care. (C) Medical social services ... (1) Assessment of social and emotional factors (2) Assessment of relationship between requirements and availability of community resources (3) Appropriate action to obtain available community resources to assist in resolving the beneficiary's problem. (4) Counseling services that are required by the beneficiary. (D) 	<p>Part 199.6 Authorized providers</p> <p>Hospice programs must be Medicare approved and meet all Medicare conditions of participation (42 CFR part 418) in relation to CHAMPUS patients in order to receive payment under the CHAMPUS program.</p> <p>May be either a public agency or private organization which:</p> <ul style="list-style-type: none"> (A) is primarily engaged in providing care and services described under Sec 199.4(e)(19) and makes such services available on a 24-hour basis. (B) Provides bereavement counseling for the immediate family or terminally ill individuals. (C) Provides for such care and services in individuals' homes, on an outpatient basis, and on a short term inpatient basis. (4) Have an interdisciplinary group composed of (1) physician; (ii) registered professional nurse; (iii) social worker, (iv) pastoral or other counselor. (5) Maintains central clinical records on all patients. (7) The hospice and all hospice employees must be licensed in accordance with applicable Federal, state and local laws and regulations 	<p>Hospice</p> <p>Must meet Medicaid definition of hospice care.</p>
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	Counseling services provided to the terminally ill individual and the family member or other persons caring for the individual at home. Bereavement counseling is not reimbursable (E) Home health aide services and homemaker services

Additional Services

Child life services at home	
Massage therapy	
Music therapy	
Acu-puncture	

Equipment and Structural Alterations

<p>Durable equipment and durable medical equipment</p>	<p>Part 199.5 TRICARE Extended Care Health Option (ECHO) July 28, 2004</p>	<p>(g)(2) Equipment (i) The TRICARE allowable amount for durable equipment and durable medical equipment shall be calculated in the same manner as durable medical equipment allowable through Sec 199.4 (ii) Allocating equipment expense. The ECHO beneficiary...may, only at the time of the request for authorization of equipment, specify how the allowable cost of the equipment is to be allocated as an ECHO benefit. The entire allowable cost...may be allocated in the month of purchase.. or may be prorated</p>	<p>Part 199.2 -Definitions. <u>Durable equipment</u>. A device or apparatus which does not qualify as durable medical equipment and which is essential to the efficient arrest or reduction of functional loss resulting from, or the disabling effects of a qualifying condition <u>Durable medical equipment</u>. Equipment for which the allowable charge is over \$100 and which (1) Is medically necessary for the treatment of a covered illness or injury; (2) Improves the function of a malformed, diseased, or injured body part, or retards further deterioration of a patient's physical condition; (3) Is primarily and customarily designed and intended to serve a medical purpose rather than primarily for transportation, comfort or convenience; (5) Provides the medically appropriate level of performance and quality for the medical condition present.</p> <p>(c)(7)(n) Equipment adaptation. The allowable equipment purchase shall include such services and modifications to the equipment as necessary to make the equipment usable for a particular ECHO beneficiary.</p> <p>(iii) Equipment maintenance. Reasonable repairs and maintenance of beneficiary owned or rented durable equipment or durable medical equipment provide by this section shall be allowed while a beneficiary is registered in ECHO</p>
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Part 199 4 – Basic Program	<p>(d)(3)(ii) Durable medical equipment. Ordered by a physician for the specific use of the beneficiary, and which complies with the definition of Durable medical equipment in sec 199.2 and which is not otherwise excluded by this regulation qualifies as a Basic Program benefit.</p> <p>(iii) Medical supplies and dressings (consumables). Such items must be related directly to an appropriate and verified covered medical condition of the beneficiary.</p> <p>(iv) Oxygen. Oxygen and equipment for its administration are covered</p>	
Structural alterations to dwelling	<p>Part 199 5 - TRICARE Extended Care Health Option (ECHO) July 28, 2004</p>	<p>(d)(3) Structural alterations Alterations to living space and permanent fixtures attached thereto, including alterations necessary to accommodate installation of equipment or to facilitate entrance or exit, are excluded.</p>
	Part 199 4 – Basic Program Benefits	(g)(54) Excluded...Elevators or chair lifts.

Transportation

Transportation by other than ambulance	Part 199.4 Basic Program Benefits	(g)(67) Excluded ... All transportation except by ambulance ...except as authorized in paragraph (e)(5) of this section.	(d)(v)(B) Vehicles such as medicabs or ambucabs function primarily as public passenger conveyances transporting patients to and from their medical appointments. No actual medical care is provided to the patients in transit. These types of vehicles do not qualify for benefits for the purpose of CHAMPUS payment.

MEDICAID HOSPICE PROGRAM

Eligibility – Eligible for Part A Medicaid, physician certifies terminally ill and probably less than 6 mos to live, sign agreement for hospice care foregoing disease directed care, use Medicaid approved hospice.

Services physician, nursing care, medical equipment, medical supplies, drugs for pain and symptom control, short term stay in hospital (including respite care for 5 days at a time w/tn no limit on the number of stays per year), home health a.d, homemaker, physical and occupational therapy, speech therapy, social work, dietary counseling, grief counseling for patient and family.

Costs - \$5 per Rx, \$5 per hospital day

APPENDIX 5



CHILDREN'S HOSPICE INTERNATIONAL

901 NORTH PITT STREET • SUITE 230 • ALEXANDRIA • VIRGINIA • 22314 • USA
800.2.4.CHILD • FAX: 703.684.0226 • INFO@CHIONLINE.ORG • WWW.CHIONLINE.ORG

MEMORANDUM

Date: August 17, 2004

To: mCare Planning Team

From: Zohreh Saunders
Deborah Kurnik

Subject: "Services/Resources Proposed in Developing CHI PACC® Models" Chart

The attached comparison chart is one method of looking at the range of services that may be covered by Medicaid under a waiver or through the Medicaid State Plan benefit. However, the state-by-state comparison may be misleading for the following reasons:

- 1 **To date none of the CHI PACC states included in the list have received CMS approval to implement their Medicaid waiver program.** Florida did receive approval to offer a modified CHI PACC program to the SCHIP (State Child Health Insurance Program) They are currently serving about 6 children in this program.
- 2 The CHI PACC states were originally encouraged to develop Section 1115 proposals (research and demonstration models) that would enable them to restructure service delivery, add new services, and request waivers of other aspects of the Medicaid program for the target population in order to serve them more effectively. Florida and Utah submitted their proposals in 2001 and 2002, respectively, to the Centers for Medicare & Medicaid Services (CMS). Dennis Smith, the Director of the Medicaid Section of CMS, recently suggested that the states use another vehicle, such as a **home and community-based waiver to obtain approval for the addition of services not currently available to the target population.** Florida and Utah are returning to the drawing board to determine how best to accomplish their goals for the CHI PACC program using another type of Medicaid waiver. Kentucky, Colorado, and New York are also reconsidering their options.
- 3 Although the chart reflects the information currently available from the CHI PACC states, **only Florida, Utah, and Kentucky have completed the design of their service package.** The services were designed to be included in their 1115 proposals. As they will have to use another type of proposal—most likely a home and community-based waiver or a freedom-of-choice waiver—to obtain approval from CMS for the addition of new services, it is unlikely the states will be able to use Medicaid dollars to fund bereavement services, since the service is directed toward the parents or other family members and not the child. Nevertheless, most of the other services in the original design will likely be covered under the new waiver proposals. Since bereavement services are an essential component of CHI PACC programs, the programs will look to other sources of funding for bereavement services.
- 4 **The national CHI PACC program recommends that the following services should be available to the target population:**
 - I. An integrated coordinated continuum of care involving:

- Home care
- Outpatient care
- Community-based care
- Respite care
- Social and supportive services
- Acute care
- End-of-life care
- Bereavement follow up care

II. An interdisciplinary team involving and coordinating the following services:

- Pediatric palliative care physicians
- Pediatric physician specialists
- Nurses
- Social Workers
- Chaplains
- Pediatric Therapist Specialists (Music, Art, Play, etc.)
- Psychologists
- Allied Therapists (PT, OT, Speech, Dietary, etc)
- Home health aides, home makers
- Volunteers
- Laboratory
- Medications and biologicals
- Durable Medical Equipment
- Medical Supplies
- Communication supports (translators, telemedicine)
- Complementary therapies (massage, acupuncture, guided imagery, etc.)
- Anything else to sustain presence in the community

III. Specific pediatric family support services including:

- Day care
- In-house/community-based respite care
- Caregiver support
- Family support (for traditional and non-traditional families, for long distance care giving needs)
- Community services to prevent unnecessary institutionalization and enhance quality of life
- Care for siblings
- Coordination with schools
- On-call system

IV. Essential services accessible 24 hours a day, 7 days a week.

The comparison chart lists some, but not all of these services and methods of delivery. Neither the chart nor the above list of comprehensive CHI PACC services differentiates between the services that are available through the state's regular Medicaid program or the child's health insurance benefit. Furthermore, the two lists do not differentiate service and place of service. The Medicaid program is structured such that each state must offer/provide mandatory services to mandatory coverage groups. The state may also offer optional services to the mandatory coverage group, and persons in optional coverage groups. Through various waivers directed to a specified target group, the state may offer additional services. The federal government provides matching funds for the mandatory services and the optional services covered in the Medicaid approved State Plan and the waiver services as approved by the federal government.

Many of the services on the comparison chart are the additional services that would be offered to the CHI PACC target population through an approved waiver.

It is also important to know that children under 18 who are covered by Medicaid have a special dispensation through the EPSDT (Early Periodic Screening, Diagnosis, and Treatment services). The state must provide any medically necessary services that may be offered under Medicaid as an optional or mandatory service, even if the state does not specifically cover that service in its State Plan. It is left to the state to define what is medically necessary and the approval process for the service.

Thus the comparison chart as labeled may not reflect all the services that a child with a life-threatening condition would be able to receive under the state's Medicaid program (see page 4 of this memo). It might be better to list on the chart only the new services that will be added to the Medicaid program to meet the unique needs of the target population, which are primarily offered as an alternative to institutional-based care.

- 5 The labeling of services in the first column of the state-by-state comparison chart can be confusing because **similar services may be named or defined differently**. For instance, "Social Work/Counseling" may be intended to encompass family, caregiver, individual, group, and bereavement counseling or it may only mean counseling for some of those categories

Medicaid Services

Mandatory Services (42CFR 440.10 to 440.50)

- Inpatient hospital Services (other than an institution for mental illness)
- Outpatient hospital services and rural health clinic services
- Laboratory and X-ray services
- Nursing facility services for individuals age 21 or older (other than an institution for mental illness)
- EPSDT (early and periodic screening and diagnosis and treatment)
- Family planning services and supplies
- Physician services and surgical services of a dentist

Optional Services (42CFR 440.60 to 440.170, 440.185)

- Medical care or other remedial care provided by licensed practitioners (chiropractors)
- Home health services (nursing, home health aide, medical supplies & equipment, PT, OT, speech, audiology, etc.)
- Medical rehabilitation facility
- Private duty nursing services
- Clinic services
- Dental services
- Physical therapy, occupational therapy, services for speech, hearing and language disorders)
- Prescribed drugs, dentures, prosthetic devices, and eyeglasses
- Diagnostic, screening, preventive ad rehabilitative services
- Inpatient hospital and nursing facility services for individuals age 65 or over in an institution for mental disease
- Intermediate care facility services for the mentally retarded (ICF/MR)
- Nursing facility other than in institutions for mental diseases.
- Inpatient psychiatric services for individuals under age 21.
- Nurse midwife services
- Nurse practitioner services
- Personal care services
- Targeted Case Management
- Respiratory care for ventilator dependent individuals
- Any other medical care or remedial care recognized under state law and specified by the Secretary
 - Transportation and travel expenses (meals, lodging, attendant)
 - Services furnished in a religious non medical health care institution
 - Skilled nursing facility services for individuals under age 21
 - Emergency hospital services
 - Critical access hospital
 - Hospice

Home and Community-Based Waiver Services (1915c) (including but not limited to)

- Case management
- Home maker
- Home health aide
- Personal care
- Adult day health
- Habilitation
- Respite Care
- Day treatment
- Expanded habilitation

Freedom of Choice Waivers (1915b)

May offer all or some of the mandatory and optional services covered under the State Plan through a specified delivery system such as managed care or primary care physician program. The waiver allows a state to limit the client's choice of providers to those of the specified delivery system.

Services/Resources Proposed in Developing CHI PACC® Models

Service Type	Utah	Kentucky	Florida	Colorado	New York	mCare
State Medicaid Services	X	X	X	X	X	
Respite	X (includes family choice)	X	X		X	
Family/Caregiver Counseling	X	X	X			
Individual Counseling	X	X	X			
Group Counseling		X	X			
Bereavement Counseling	X	X	X	X	X	
Pain and Symptom control/Palliative Care	X	X	X	X		
Support Therapies	X (Expressive Therapies)		X		X (Creative Arts and Therapies)	
Hospice in Home Nursing	X		X			
Hospice in Home Personal Care			X			
Volunteer Support			X	X		
Collaborative Care Planning (Coordinator)	X	X	X	X	X	
Patient Medical Management		X				
Direct Nursing Services	X	X		X		
Transportation	X	X				
Pharmacy	X	X		X		
Plan of Care	X				X	
Family Child Education					X	
Social Work Counseling		X		X	X	
Spiritual Care (Chaplain Services)		X		X	X	
Advocacy for Child/Family Needs					X	
Standards of Care					X	
Provider Education	X	X	X	X	X	
Tricare Health Benefits						X
Dietary Support		X (Nutritional Support)		X		
Physical Therapy		X		X		
Speech Therapy		X				
Respiratory Therapy		X				
Occupational Therapy		X		X		
Medical Director				X		
Insurance Navigator	X					
Resource Coordinator		X				
Disposable Supplies	X	X				

Durable Equipment	X	X				
Food and Lodging Vouchers		X				

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APPENDIX 6

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APPENDIX 7

**Comparison of ICD-9 Diagnostic Codes Used to Identify Children with Life-Threatening or Life-Limiting or Complex Chronic Conditions By Five CHI PACC Programs
and Chris Feudner (July 6, 2004)**

ICD-9 Category	ICD-9 Description	ICD-9 Diagnosis Codes				
		Utah	Feudner	New York	Kentucky	Virginia
Infections	Herpes simplex virus, type 1, disease	042	042	14C 0-230.1	042	042
	Herpes simplex virus, type 1, disease	14C 0-230.1	14C 0-230.1	14C 0-230.1	150 0	150 0
					153 11	153 11
					155 0	155 0
	Malignant neoplasm of liver and intrahepatic bile ducts	156 0	156 2			
	Malignant neoplasm of pancreas	157 0	157 9			
	Malignant neoplasm of retroperitoneum and peritoneum	158 0	158 8			
	Malignant neoplasm other & ill defined sites n digestive orgs	159 0	159 9			
	Malignant neoplasm of trachea, bronchus and lung	162 0	162 9			
	Malignant neoplasm of thymus, heart and mediastinum	164 0	164 9			
	Malignant neoplasm of other & ill defined sites in respiratory	165 0	165 9			
	Malignant neoplasm of bone and articular cartilage	170 0	170 9			
	Malignant neoplasm of connective and other soft tissue	171 0	171 9			
	Malignant neoplasm of lesions	176 0	186 9			
	Malignant neoplasm of kidney & other unspecified urinary organs	189 0	189 9			
	Malignant neoplasm of eye	190 0	190 9	190 0-199 1		
					191 0	191 6
					191 7	191 9
					192 0	192 1
	Malignant neoplasm of brain	191 0	191 9			
	Malignant neoplasm other & unspecified parts of nervous system	192 0	192 9			
	Malignant neoplasm of thyroid gland	193				
	Malignant neoplasm other endocrine glands & related structures	194 0	194 9			
	Malignant neoplasm of other ill defined sites	195 0	195 8			
	Malignant neoplasm without specification of site	199 0	199 1			
					199 1	199 1
					201 9	202 8,
					204 0	205 0,
					205 1	208 0,
						208 9
	Malignant neoplasm of lymphatic & hematopoietic tissue	200 0	208 9	200 0-208 9		
	Hemangioma and lymphangioma any site				228 0	
					237 0	237 7,
	Neoplasms of brain and spinal cord	237 5			238 0	
	Neoplasms of unspecified nature				239 6	239 7
						139 5
Endocrine Metabolic	Dialysis melitus	250 0-250 93	250 0-250 1			
	Dwarfism/bone & joint anomalies	259 4	259 4			
	Amino acid metabolism	270 270 0	270 270 7	x		
	Carbohydrate metabolism	271 0 271 9	271 0 271 9	x		
	Lipid metabolism	272 0 272 9	272 0 272 9	272 0 272 9		

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	<i>f</i> Budnir	Utah	New York	Kentucky	Virginia	Florida
~ disorders	2727					x
Disorders of mineral metabolism	2750 2753				x	x
Cystic fibrosis	2770				x	x
~ fat metabolism	2770				x	x
Endocrine Metabolic (continued)	2772 2774				x	x
M. I. & S. J. (continued)	2775 2779				x	x
Immunology, n.r., n.s., c.t.	2775 2779				x	x
Deficiency of cell-mediated immunity	2777 0-2779				x	x
Complement immuno deficiency	2791 - 27919				x	x
Unspecified immuno deficiency	2792				x	x
	2793				x	x
Blood	2820 2824				x	x
Sickle-cell anemia	2825-2826	28260-28269			x	x
Aplastic anemia	2840	2840			x	x
Hematology & Immuno-deficiency	2860-2863				x	x
Coagulation defects	2860-2863				x	x
Hereditary immunodeficiency (diseases of white blood cells)	2881-2882				x	x
	3180 3190				x	x
Central nervous system degeneration & disease	3300 3379	3310-3319	3300 3301		x	x
	3301				x	x
Other cerebral degenerations	3350-3359	3350-3359	3350 3359		x	x
Anterior horn ce. disease	3430-3439	3432	3432		x	x
Plantar cerebral palsy Quadriplegic ~	3439	3439	3439		x	x
Plantar cerebral palsy unspecified	3450 3459				x	x
	3461-3462				x	x
Epilepsy					x	x
					x	x
Nervous					x	x
Neuromuscular					x	x
					x	x
Unspecified conditions of nervous system	3482-3484	3480-3489	3489		x	x
Muscular or strength & brain myopathies	3590 3593	3590 3591	3590 - 3592		x	x
					x	x
Unspecified hypertensive heart disease	4028				x	x
Acute myocardial infarction	410				x	x
Circulatory					x	x
Cardiovascular					x	x
Coronary atherosclerosis	4140				x	x
Chronic ischemic heart disease NIDS	4149				x	x
Chronic pulmonary hypertension	4160				x	x
Chronic pulmonary heart disease	4169				x	x
Cardiomyopathy	4253 4254				x	x
Conduction disorders	4250-4254	4250-4254	4259		x	x
	4260 4266				x	x
	4274				x	x

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	Fleldner	Utah	New York	Kentucky	Virginia	Florida
Hypothyroidism	427 6 427 9		427 5 427 9	427 9		
Congestive heart disease			428 0		429 0 429 1	
Circulatory system (continued)			429 1	429 0 - 429 9	429 3 429 9	
Myocarditis unspecified				429 0-429 9	429 3 429 9	
Pericardial & pleural effusion				431		
Gene and unstable arteriosclerosis				436		
Acute febrile in = exanthem subitum syndrome	446 1			437 9		
Asthma				440 9		
Chronic airway obstruction not elsewhere classified					493 0-493 9	
Chronic respiratory failure			496		496	
Other diseases of the respiratory system					519 1	
Digestive					519 1	
Inflammatory bowel disease	553 2				553 3	
Chronic liver disease and cirrhosis	555 0-556 9					
Diphagmatic hernia	551 4-571 9	571 4 571 9				
Acute renal failure	585	585			574 5 571 8	
Chronic renal failure		586			585	
Genitourinary					586	
Renal failure unspecified						
Anencephalus					373 3	
Spina bifida						
Other congenital anomalies of nervous system						
Brain & spinal cord malformations						
Spina bifida						
Other congenital anomalies of nervous system						
Heart & great vessel malformations						
Gulib's cords anomalies & cardiac septal closure	745 0-745 3					
Other congenital anomalies of the heart						
Hypoplastic left heart syndrome	746 7					
Other specified anomalies of the heart	746 85-746 86					
Other congenital anomalies of the heart	747 41					
Respiratory malformations						
Other congenital anomalies respiratory sys						
Congenital anomalies gastrointestinal	748 3-748 5					
Other congenital anomalies digestive sys	750 3					
Congenital anomalies gastic & intestinal	751 1-751 3					
Other congenital anomalies gastic & intestinal	751 6-751 8					

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	Feudtner	Utah	New York	Kentucky	Virginia	Florida
Congenital anomalies, renal	753.0-753.9	753.0-753.1			753.1-753.9	x
Congenital anomalies of urinary system	756.0-756.5		756.1-756.9	756.0	756.1	x
Congenital musculoskeletal		756.51			756.5	756.6
Osteogenesis imperfecta	756.6					x
Aromatases of chromosomal anomalies	756.7-756.71					x
Congenital anomalies, skin	756.8				756.8	x
Aladus syndrome	756.1				756.1	
Edward's syndrome [and other chromosomal abnormalities]	756.2				756.2	753.3
Multiple congenital anomalies	759.7	759.7	759.7-759.9	759.7	759.7	x
Other specified anomalies			759.83		759.81-759.89	759.8
Fragile X Syndrome			759.9		759.9	x
Congenital anomaly, unspecified	759.9	759.9			760.0-760.8	
Other maternal specified conditions affecting fetus/newborn					761.0-761.9	
Fetus/newborn affected by maternal complications of pregnancy	765				765.0-765.9	765.0
Extreme immaturity	765.1				765.10-765.19	765.1
Other preterm infants					766.5-768.9	
Birth asphyxiation					769	769
Respiratory distress syndrome in newborn			770.7	770.7	770.0-770.9	770.7
Chronic respiratory disease arising in perinatal period					771.8	
Other infections specific to the perinatal period					777.5-777.6	
Necrotizing intestinal perforation					994.7	
Asphyxiation & strangulation					995.50-995.59	
Child maltreatment syndrome					995.55	
Shaken infant syndrome					996.85	
Complications of transplanted bone marrow					E910	
External Injury, Accidental drowning or submersion						

Codes in bold for Utah and Florida indicate that, in addition to diagnosis, other factors such as hospitalization or utilization of other services (e.g., dialysis, etc.) are required to identify the child as having a life threatening condition.

Sources: FEUDTNER, Chris et al. "Deaths Attributed to Pediatric Complex Chronic Conditions: National Trends and Implications for Supportive Care Services," Pediatrics, Vol 107 No 6, June 2001, p107

UTAH - "State of Utah Application for a Section 1115 Research and Demonstration Program Promoting HOPE for Utah Children A ChildPACC Project February 12, 2003

NEW YORK - Milken USA Inc. New York NY Kate + Ann Bruce Ryerson Palliative Care for Children with Life-Limiting Illness: An Actuarial Evaluation of Costs for a New York State Medicaid Demonstration Project, June 10, 2003

	Kentucky	Florida	Utah	New York	Kentucky	Virginia	Florida
KENTUCKY - PACC Diagnosis Codes for Potential Program Candidates "PACC Diagnosis Severity Index January 2004							
FLORIDA - Partners in Care - Agency for Health Care Administration: Florida Department of Health							
Request Program for All-Inclusive Care for Children Florida "October 24, 2002							
VIRGINIA - For "ICD-9-CM" diagnosis that will reflect the NAPCC "targeting, when" from a list of death in Virginia between 1992-1998 in order of severity. Is "at least 2 deaths occurring during the relevant period.							

APPENDIX 8

Estimating the Size of the Population of Children Served by the J.S. Military Life-Threatening Conditions Who Might Benefit from CHIPACC Services

August 10, 2004 - Prepared by Zohreh Saunders for Children's Hospice International

Estimating the Size of the Population of Children Served by the U.S. Military Life-Threatening Conditions Who Might Benefit from CHI PACC Services

August 10, 2004 - Prepared by Zohreh Saunders for Children's Hospice International

Source	United States	Percentage	Military Health System	Tri-Care
Estimated U.S. population				
U.S. Population: 0-18	28,421,936		< 300,000	~ 200,000
U.S. Population: 0-6	7,325,430			
Percent of U.S. population in metro areas	16.13% 690	0.006		
Percent of population in non-metro areas	22% 951,744	0.81%		
Persons per household	3.19	0.19%		
Households with children	2.59			
Median household income	38,072,155			
U.S. population below poverty	\$24,954	0.12%		
Children below poverty (\$4,600 per 3 person household in 2001)	34,896,316			
U.S. population non-white	15,043,689	0.20%		
Children without health insurance	70,074,055	0.24%		
Total U.S. population enrolled in Medicaid	9,237,000	0.12%		
Population in military				
Medicaid population enrolled in managed care	39,604,366	0.14%		
Unduplicated children enrolled in Medicaid	22,732,906	0.57%		
SCAMP Enrollment	16,915,680	0.23%		
Deaths	4,601,086	0.06%		
Children 0-18 who die annually	54,556	0.0007%	1,500	~ 450
Children under age 1 who die annually	27,568	0.0003%	762	~ 450
Estimated number of children who die annually of complex chronic conditions				
Estimated number of U.S. children die annually of designated life-threatening diseases	15,000	0.0002%	416	~ 249
Estimated number of children with a severe chronic condition	18,204	0.00025%	503	302
Estimated number of children with a severe chronic condition	4,374,183	0.01%	38,000	22,500
Estimated number of children with a severe chronic condition	1989 GAC report		27,553	~ 3,732
Estimated number of children with a severe chronic condition	Estimated 1998 report		27,553	~ 3,732
CD Socioeconomic categories	~ 275,745	0.01%	33,840	2

Prevalence of serious serious conditions among Utah children	14.14% Utah, State, 2001 National Utah prevalence rates, C Novin, Utah)	14,143,000	0.01541	30,814	10,458
CSHCN Conditions among Tricare 0-18 employees	Williams, Pediatrics 2004	16,634,849	0.23300	460,300	276,353
CSHSN With Functional Limitation 0-18	Williams, Pediatrics 2004	3,941,736	0.05450	109,300	65,400
Estimated number of children with chronic life-threatening conditions	ChPPs paper, March 2001	446,090	0.00617	12,233	+ 4,100
All hospital discharge cases for children with a designated life-threatening diagnosis	Extrapolated from Utah hospital discharge data	218,200	0.00302	5,034	3,620
Children who have with chronic life-threatening conditions	K estimates * 10,000 Extrapolated from survey of Utah pediatric specialists	72,235	0.00100	1,997	1,196
Children not expected to survive childhood because of a life-threatening condition	60,266	0.00083	1,667	1,000	
Children not expected to survive childhood because of a life-threatening condition as defined	75,869	0.00105	2,098	1,250	
Life-Threatening Conditions - Daily Census	139,081	0.00192	3,846	2,308	
Estimated number of children who would benefit from palliative care	-	6,000	0.00018	166	100
Estimated number of children with 6 months of care with complex chronic conditions	Feudner et al.	5,000	0.00057	138	83

Engineering in Service of the Population of Chilean Marshes and the San Marcos River. A Joint Report from the UNDP/FAO Program Services

March 11 - 2004 Prepared by Lethen Sanderson by Order of the Board of Education
for the purpose of use in grades 1-3. Date used 3/11/04
41% of 2nd grade population participating in MA assessment

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Section	United States	Kenneth, States	Research, States	United States
Estimated number of children over 12 years from age 12 to 18	1909 SA report from 1960 census	600 CC J	24 000	6 237
No. O's indicating a single-parent household	123 66	25 609	7 632	
Percent of selected sources reporting Urban Center	1142 303	23 400	6 930	1339
Estimated, and o. 1960, U.S.A.			13981	221
Estimated, and o. 1960, U.S.A.	A45 101	8 468	2 782	207
Estimated, and o. 1960, U.S.A.	213 203	4,892	1 361	3267
Other and eye with non. de provy	72 265	1,917	454	432
Conditions	CC 265	1 265	379	464
Condition not expected to survive, diagnosed because of a new measure of condition	130 CC 10 3 24	130 CC 10 3 24	2 821 1 593	867 473
Child can not expect to survive, diagnosed because of a new measure of condition	Alcoholism			
Because of a new measure of condition	Champs phys. heart 2000	6000-6000	126 466	37 4650
Institutionalized	Faithline, et al.	50X	105	3f
Estimated, and o. 1960, U.S.A.				
Estimated, and o. 1960, U.S.A.				
Estimated, and o. 1960, U.S.A.				

APPENDIX 9

Data Gathering Recommendations for the DOD mCare Project
Children's Hospice International – Z. Saunders
July 15, 2004

In conducting a feasibility study to determine how best the CHI PACC model of care can be implemented for the children and family of military members, it is important to (1) identify the potential target group, (2) estimate its numbers, and (3) estimate how this group has historically used the available medical and support services. Lastly, it will be important to know (4) the average monthly cost of these services to Walter Reed Hospital, Tri-Care, and the families themselves. (Items 3 and 4 will be addressed at a later time).

Identifying the Potential Target Population

The CHI PACC model is intended to serve children with life-threatening conditions and their families from diagnosis to bereavement, if cure is not attained. There are currently no universal definitions of children with life-threatening conditions. A number of the CHI PACC grantee programs have attempted to define the group in a broad way for admission criteria, and through more specific diagnostic criteria to compile historical costs and characteristics of a proxy population.

State/Region	Eligibility Criteria
Colorado	Under development
Florida	Children with life-threatening conditions in the Children's Medical Services Network (CMSN) referred to the program by primary care physician
Kentucky	Medicaid-eligible children certified by a physician to have a diagnosis of a life-threatening illness/condition
New York	Children eligible for 1915 (c) home and community-based services waiver (Long Term Home Health Program waiver)
Utah	Determination by treating physician that the child has a medical condition so serious it is likely the child will not live beyond age 18. <i>Child who might benefit may have a diagnosis</i> <ul style="list-style-type: none">- <i>for which a cure is possible, but not certain (e.g. Cancer);</i>- <i>for which there is no known cure, but treatment may increase life-expectancy and quality (e.g. cystic fibrosis, muscular dystrophy, HIV);</i>- <i>for which treatment is palliative from the beginning (e.g. neurodegenerative disorders, Battens Tay-Sachs),</i>- <i>which is not progressive but may cause life-limiting complications (e.g. severe cerebral palsy, brain trauma or damage)</i>
Virginia	Under development
New England	Under development

The 2003 Institute of Medicine report, *When Children Die*, defines life-threatening conditions as those that "(1) carry a substantial probability of death in childhood, although treatment may succeed in curing the condition or substantially prolonging life, and (2) are perceived as potentially having a fatal outcome." 4(IOM p. 37). Some use the term life-limiting which can connote that there may be limitations on the quality of life and daily living, but not necessarily premature death. There are also terms such as life-shortening or fatal medical conditions which may seem clear to clinicians, but not parents.

4 Institute of Medicine, *When Children Die, Improving Palliative and End-of-Life Care for Children and their Families*, Institute of Medicine of the National Academies, 2003 p. 37.

Himelstein⁵ identifies "conditions appropriate for pediatric palliative care" as follows:

Conditions for which curative treatment is possible but may fail

Advanced or progressive cancer or cancer with a poor prognosis

Complex and severe congenital or acquired heart disease

Conditions requiring intensive long-term treatment aimed at maintaining the quality of life

Human immunodeficiency virus infection

Cystic fibrosis

Severe gastrointestinal disorders or malformations such as gastrochisis

Severe epidermolysis bullosa

Severe immunodeficiencies

Renal failure in which dialysis, transplantation, or both are not available or indicated

Chronic or severe respiratory failure

Muscular dystrophy

Progressive conditions in which treatment is exclusively palliative after diagnosis

Progressive metabolic disorders

Certain chromosomal abnormalities such as trisomy 13 or 18

Severe forms of osteogenesis imperfecta

Conditions involving severe, nonprogressive disability, causing extreme vulnerability to health complications

Severe cerebral palsy with recurrent infection or difficult-to-control symptoms

Extreme prematurity

Severe neurologic sequelae of infectious disease

Hypoxic or anoxic brain injury

Holoprosencephaly or other severe brain malformations

Estimating the Numbers in the Potential Target Population

Just as there are no uniform definitions of children with life-threatening conditions, the number of children with such conditions in the United States varies. Estimated numbers range significantly. On the high end is a count of 1.3 million based on the National Association of Children's Hospitals and Related Institutions' (NACHRI) estimate that 1.9% of children under age 17 have a severe chronic illness. On the low end, estimates from the United Kingdom indicate that 10:10,000 children can benefit from hospice care, which translates to about 72,000 children in the U.S. based on the 2000 census. This number is based on utilization in the U.K. which has more widespread access to freestanding hospice.

According to a 1989 report of the General Accounting Office (GAO), 10-15% of all children have chronic health conditions and "about 10% of them—or 1 million children—have a severe form of it."⁶ Although the report does not define chronic health conditions, it surveyed families whose children had the following diagnoses: juvenile-onset diabetes, asthma, spina bifida, cleft palate craniofacial anomaly, congenital heart disease, leukemia, end-stage renal disease, sickle cell anemia, cystic fibrosis, muscular dystrophy, and other. This list indicates the GAO definition of chronic health conditions is broader than what the CHI PACC programs have proposed as it includes conditions that are not necessarily life-threatening such as cleft palate and asthma.

⁵ B. Himelstein, J. Hilden, A. Boldt, D. Weissman, "Medical Progress Pediatric Palliative Care," *New England Journal of Medicine*, 350:17, April 2004.

⁶ GAO, "Home Care Experiences of Families with Chronically Ill Children, GAO/HRD89-73, June 1989

The ChiPPS group, a subcommittee of the National Hospice and Palliative Care Organization, estimates 500,000 children in the U.S. have chronic life-limiting conditions. This number includes children who may not face premature death, but whose quality of life is impaired by their condition.

Feudtner⁷ takes a different approach by defining the group of infants, children, and young adults that may benefit from palliative care supportive services, as those who have "complex chronic conditions. In this analysis, he estimates that 15,000 infants, children, adolescents, and young adults (includes those up to age 24) die each year from conditions that would benefit from pediatric supportive care services. This is based on a review of death certificates among 0-24 age group in the period 1979-1997 where the cause of death is within specified ICD-9 diagnosis codes classified as complex chronic conditions.

At the same time, he attempts to estimate the average number of children with complex, chronic conditions who would be eligible for hospice care. "Because most infant deaths occur within hours to days of birth, infants who die because of CCC's spend few days alive in the 6-month period of time during which they would have been eligible for hospice insurance benefits"⁸ Thus, there are more adolescents and young adults who might benefit from supportive care than infants or children. Feudtner estimates that based on deaths in 1997, on any given day 5,000 are living within the last 6 months of life. This translates to approximately 20,000 individuals 0-24 who in the course of a year might be eligible for hospice services because they are within 6 months of death. This number may be slightly inflated for use by the CHI PACC projects as most of the CHI PACC projects intend to serve the age group up to age 18 or in some cases to age 21.

Because the intent of the CHI PACC projects is to reach children and families earlier than the 6-month period before death, Feudtner estimates are likely too low as there are many children who might benefit from palliative care and support services much earlier in the trajectory of their disease.

Feudtner Estimates of Number of 0-24 year olds Eligible for Hospice at a Point in Time

	Infants	Children	Adolescents/Young Adults	Total
Cancer	47	541	1139	1727
Non Cancer	1050	873	1409	3332
Total	1097	1414	2548	5059

In summary, the estimates of the number of children 0 to age 21 in the U.S. who may be potential candidates for participation in a CHI PACC program, from the point of diagnosis probably falls within the low estimate of 20,000 by Feudtner and the high estimate of 400,000 by the ChiPPS group.

Feudtner's list of ICD-9 diagnosis codes was published just as the CHI PACC states were developing their own lists and his list was studied and utilized in part by all the CHI PACC states. Before the publication of Feudtner's article, Utah compiled a similar list of diagnostic codes based on the records of a home health/hospice agency that served this group of children and an analysis of nine years of vital statistics data for the State of Utah. Utah compiled the number of children under the age of one and those age one to 18 who died between 1990-1998 whose underlying cause of death based on ICD-9 codes was included in the range of life-threatening conditions in the table on the following page. Utah identified an average of 181 child deaths per year from these conditions. About 66 percent of the deaths occurred among those under age one and 34 percent for age one to eighteen.

This list of diagnosis (See Table 1) codes was then run against the Medicaid claims data for CY2000 to identify the number of children 0 -18 who had a paid claim for a Medicaid service with one of the identified diagnosis codes in one year. This run identified 1680 unduplicated children with one of these diagnoses on a fee-for-service claim which represents 1.3% of the children on Medicaid. This number appeared much higher than

7 C. Feudtner, "Deaths Attributed to Pediatric Complex Chronic Conditions: National Trends and Implications for Supportive Services. *Pediatrics*, Vol 107, No. 6, June 2001.

8 Ibid

would be expected based on Utah hospital discharge data, a survey of pediatric specialists, the number of deaths of children due to a life-threatening condition, and an extrapolation of Feutdner's data regarding the number of children within six months of death. Therefore, we concluded that diagnosis alone is not sufficient to identify the potential number of children in the Medicaid program who might be classified as having a life-threatening condition.

Table: A Sample of Life Threatening Illnesses in Children by ICD - 9 Codes and Frequency of Mortality in Utah 1990 - 1998 by Age Group (Revised 6/27/01)

Illness	ICD - 9	Mortality Frequency	
		Under 1	Age 1 - 18
Infectious and Parasitic Diseases			
Human Immunodeficiency Virus, Type 2	042	0	3
Subtotal		0	3
Neoplasms			
Malignant Neoplasm of lip, oral cavity, pharynx	140.0 - 149.9	0	1
Malignant Neoplasm of digestive organs & peritoneum	150.0 - 159.9	1	5
Malignant Neoplasm of respiratory & intrathoracic organs	160.0 - 165.9	1	2
Malignant Neoplasm of bone, connective tissue, skin, etc	170.0 - 176.9	0	26
Malignant Neoplasm of testis	186.9	0	2
Malignant Neoplasm of kidney	189.0	1	3
Malignant Neoplasm of other & unspecified sites	190.0 - 199.1	6	68
Malignant Neoplasm of lymphatic & hematopoietic tissue	200.0 - 208.9	0	80
Neoplasms of Uncertain Behavior	238.9	1	0
Neoplasms of Uncertain Behavior	239.0 - 239.9	8	15
Subtotal		18	202
Endocrine, Nutritional, Metabolic, Immune Systems			
Other metabolic and immunity disorders	270.0 - 279.9	3	4
Disorders of lipid metabolism	272.0 - 272.9	0	4
Disorders of mineral metabolism	275.0 - 275.3	3	1
Lipidoses	272.7	0	3
Other & unspecified disorders of metabolism	277.0 - 277.9	4	25
Deficiency of cell - mediated immunity	279.1	1	1
Combined immunity deficiency	279.2	0	2
Unspecified immunity deficiency	279.3	1	0
Subtotal		12	40
Blood and Blood - Forming Organs			
Other specified aplastic anemias due to enzyme deficiency	282. - .3	1	1
Constitutional aplastic anemia	284.0	0	1
Other specified aplastic anemias	284.8	1	0
Genetic anomalies of leukocytes	288.2	1	0
Subtotal		3	2
Nervous System and Sense Organs			
Cerebral degenerations usually manifest in childhood	330.0 - 330.9	2	15
Other cerebral degenerations	331.0 - 331.9	1	9
Anterior horn cell disease	335.0 - 335.9	9	2
Infantile cerebral palsy, quadriplegia	343.2	0	3
Infantile cerebral palsy, unspecified	343.9	0	30
Other conditions of brain	348.1 - 348.5	8	10

Other & unspecified disorders of the nervous system	349.8 - 349	1	4
Muscular dystrophies & other myopathies	359.0 - 359.2	2	22
Subtotal		23	95

Circulatory System

Ventricular fibrillation and flutter	427.4	0	2
Other specified cardiac dysrhythmias	427.8 - 427.9	0	6
Cardiomyopathy	425.0 - 425.4	9	12
Ill-defined descriptions & complications of heart	429.0 - 429.9	5	13
Subtotal		14	33

Respiratory System

Chronic Respiratory Failure	518.83	3	5
Subtotal		3	5

Digestive System

Diaphragmatic hernia	553.3	1	0
Acute and Subacute Necrosis of Liver	570	0	2
Chronic liver disease and cirrhosis without mention of alcohol	571.4 - 571.9	2	0
Other sequelae of chronic liver disease	572.8	3	3
Subtotal		6	5

Genitourinary System

Chronic renal failure	585	1	0
Renal Failure, Unspecified	586	8	2
Subtotal		9	2

Congenital Anomalies

Anencephalus & similar anomalies	740.0 - 740.2	33	0
Spina bifida	741.0 - 741	5	3
Other congenital anomalies of nervous system	742.0 - 742.9	43	45
Bulbus cordis & cardiac septic closure anomalies	745.0 - 745.9	51	9
Other congenital anomalies of heart	746.0 - 746.9	236	51
Other congenital anomalies of circulatory system	747.0 - 747.9	41	9
Other Anomalies of larynx, trachea, and bronchus	748.3 - 748.9	100	3
Other congenital anomalies of digestive system	751.0 - 751	13	3
Congenital anomalies of urinary system	753.0 - 753.9	46	4
Anomalies of skull and face bone	756.0	0	2
Anomalies of spine	756.1-756.9	48	4
Chromosomal anomalies	758.0-758.9	119	11
Multiple Congenital Anomalies	759.7	26	3
Other specified anomalies	759.8	8	8
Congenital anomaly, unspecified	759.9	10	3
Subtotal		779	158

Conditions of the Perinatal Period

Extreme Immaturity	765.0	126	0
Extreme Immaturity, Less than 500 Grams	765.1	65	0
Chronic respiratory disease arising in the perinatal period	770.7		

Subtotal		211	4
<i>Grand Total</i>	1627	1078	549
<i>Nine Year Average</i>	181	120	61

As a result, we worked with several pediatricians and hospital-based specialists to help us refine the list of diagnosis codes to create an algorithm that would factor other elements into the list of diagnostic codes to better discriminate among those with a diagnosis and those more likely to utilize support services that we planned to offer as part of the CHI PACC program. Utah's Algorithm predicts there may be between 76,000 to 139,000 children (0-18) in the U.S. who might benefit from palliative care and support services annually. The lower figure of 76,000 is based on 18% of the population of children with life-threatening conditions on Medicaid, while the higher number of 139,000 is based on 30% of that group qualifying for Medicaid.⁹

Although the Utah Algorithm may not be the definitive method of identifying children with life-threatening conditions through the medical claims system, projecting from the Utah numbers to the U.S. population, it may provide a reasonable estimate of the potential range of children in the U.S. who may benefit from CHI PACC program and services. Extrapolating from the Utah and national data to states may also provide some indication of the potential candidates for CHI PACC program and services.

Kentucky has added further refinements to the Utah Algorithm and once we compare its results in predicting the target population, we may have a tool that can help estimate the potential number of children who may benefit from CHI PACC programs based on state or regional demographics and health care data.

Estimating the Potential Population in the Military

To begin, the *mCare* project may wish to estimate the potential population by extrapolating from national and the Utah data as a means of coming up with the potential range of children who might benefit from the *mCare* project, before undertaking a more comprehensive survey of medical charts or claims.

If medical charts or claims are used, Table 1 ICD-9 codes or the Comparison List of ICD-9 codes may be useful for the first cut. Once this data base is compiled, the Utah and Kentucky refinements, Utah Algorithm, and Kentucky Severity Index may help to better pin-point the size and characteristics (cost, utilization, profile) of the proxy target population.

⁹ In Utah's analysis a disproportionate number of deaths from life-threatening conditions occurred among children on Medicaid. Whereas 18% of children in Utah were on Medicaid, 30% of the deaths from life-threatening conditions. Virginia also tracked deaths from life-threatening conditions for all children in the State and those on Medicaid and found a similar disparity.

Table 2: Estimating the Size of the Target Population: Demographics

Descriptor	United States	Military	Pilot Site
		<i>% of US child population]</i>	<i>% of child population]</i>
Total population <i>(Source)</i>	281,421,906 <i>(US 2000 Census)</i>		
Population of children 0-18	72,325,430 <i>(US 2000 Census)</i>		
Percent of population under 18-21	(Under 18) 25.7% <i>(US 2000 Census)</i>		
Percent of population in urban areas & rural areas			
Persons per household	2.63 <i>(US 1990 Census)</i>		
Median household income	\$34,076 <i>(1995 model-based estimate)</i>		
Percent of children below poverty (\$14,600 per 3 person household in 2001)	20.8% <i>(1995 model-based estimate)</i>		
Percent population non-white	24.9% <i>(US 2000 Census)</i>		
Children without health insurance	14.9% <i>(1996 US Census Brief)</i>		

Table 3: Estimating the Size of the Target Population By Extrapolating from National Data: Child Deaths and Children with Chronic Conditions

Descriptor	United States	Military	Pilot Site
Children who die annually	53,000 <i>(Am. Acad. Of Pediatrics)</i>	<i>(State vital statistics)</i>	<i>(Extrapolate from State vital statistics)</i>
Estimated no. of children who die annually with a designated life-threatening diagnosis (<i>State Vital Statistics</i>)	18,204 <i>(Extrapolated from State Data data)</i>	<i>(1990-1999 average, Utah vital statistics)</i>	<i>(MMIS and UT vital statistics data)</i>
Estimated number of children who die annually with complex chronic conditions (<i>Feudtner, et. al.</i> excludes most perinatal diagnoses)	15,000	<i>(Extrapolate from Feudtner data)</i>	<i>(Extrapolate from Feudtner data)</i>
Estimated number of children within 6 months of death with complex chronic conditions	<i>(point in time) 5,000 (annual) 20,000</i> <i>(Feudtner, et. al.)</i>	<i>(Extrapolate from Feudtner data)</i>	<i>(Extrapolate from Feudtner data)</i>
Estimated number of children (0-17) with severe chronic illness who would benefit from palliative care. (<i>NACHRI</i>)	1,374,183 <i>(NACHRI estimates 1.9% of population)</i>	<i>(Extrapolate from NACHRI data)</i>	<i>(Extrapolate from NACHRI data)</i>
Estimated number of children with a severe chronic condition <i>(GAO report)</i>	1,000,000 <i>(GAO report 1989 & Children's Hospice International)</i>	<i>(Extrapolate from GAO report)</i>	<i>(Extrapolate from GAO report)</i>
Estimated number of children with a designated ICD-9 diagnostic code indicating a life-threatening condition. (<i>state Medicaid</i>)	1,223,746 <i>(Extrapolate from Medicaid FFS claims data)</i>	<i>(Extrapolate from Medicaid FFS claims data)</i>	<i>(Based on Utah Medicaid FFS claims)</i>
Prevalence of Various Serious Conditions Among Utah Children (<i>C. Norlin Prevalence Rates</i>)	1,114,300 <i>(Extrapolated from national/Utah prevalence rates)</i>	<i>(Extrapolate from national/Utah prevalence rates)</i>	<i>(Extrapolate from national/Utah prevalence rates)</i>
Estimated number of children with chronic life-limiting conditions. ChiPPs	446,000 <i>(ChiPPs paper, March 2001)</i>	<i>(Extrapolate from ChiPPs paper)</i>	<i>(Extrapolated from ChiPPs paper)</i>

Table 4: Estimating the Size of the Target Population by Extrapolating from Other Sources

Descriptor	United States	Military	Pilot Site
Annual hospital discharge cases for children with a designated life-threatening diagnosis (<i>Utah 1999 Hospital Discharges</i>)	218,200 <i>(Extrapolated from Utah hospital discharge data)</i>	 <i>(Based on your State's hospital discharge cases)</i>	 <i>(Extrapolated from your State's hospital discharge data)</i>
Estimated number of children who would benefit from palliative care (daily census) (<i>ChiPPs</i>)	6000-8000 <i>(ChiPPs paper, March 2001)</i>	 <i>(Extrapolate from ChiPPs paper)</i>	 <i>(Extrapolate from ChiPPs paper)</i>
Children who live with chronic life-limiting conditions (UK)	72,235 <i>(UK estimates 10:10,000)</i>	 <i>(Extrapolate from UK estimate)</i>	 <i>(Extrapolate from UK estimate)</i>
Children not expected to survive childhood because of a life-threatening condition. (Utah Pediatric Specialists)	60,266 <i>(Extrapolated from Utah survey)</i>	 <i>(Extrapolate from Utah survey)</i>	 <i>(Extrapolate from Utah survey)</i>
Children not expected to survive childhood because of a life-threatening condition as defined in the Utah Algorithm (Includes tech waiver)	139,081-75,869 <i>(Extrapolated from Utah Medicaid claims & Utah Algorithm)</i>	 <i>(Extrapolate from Utah Medicaid claims & Utah Algorithm)</i>	 <i>(Extrapolate from Utah Medicaid claims; CY2000 based on Utah Algorithm)</i>

APPENDIX 10

CONDITIONS WHICH MEET DEFINITION OF LIFE-THREATENING

The combination of ICD-9 codes and severity index creates a pool of beneficiaries for whom intensive care-coordination is essential based on medical needs, disability and/or family circumstances or expense to MHS and from which the beneficiaries eligible for mCare will be drawn.

Severity index

A: Hospitalization >2 per year, or outpatient care for condition >8 per year and functional limitation of at least one age-appropriate ADL skills of at least 50%, or need for >1 DME, or home nursing services

B: At diagnosis

Condition	ICD-9 codes	Severity index
Human immunodeficiency virus	042	A
Congenital syphilis	090.0-090.9	A
Malignant neoplasms/neoplasms	140.0-239.9	A
Disorders of metabolism (excluding diabetes mellitus)	272.7-277.9	A
Immune deficiency syndromes	279.1-279.3	A
Anemias and coagulation defects	282.0-286.9	A
Bacterial meningitis	320.0-320.9	A
Cerebral degenerations	330.0-331.9	B
Anterior horn cell disease	335.0-335.9	B
Cerebral palsy, quadriplegia	343.2-343.9	A
Unspecified conditions of brain	348.0-348.9	A
Other conditions of nervous system	349.0-349.9	A
Muscular dystrophy and other myopathies	359.0-359.4	A
Cardiomyopathy	425.0-425.9	A
Other conditions of the heart	429.0-429.9	A
Chronic respiratory failure	518.83	B
Other diseases of lung	518.89	A
Chronic liver disease	570-579.3	A
Chronic renal failure	586	A
Anencephalus and similar anomalies	740.0-740.2	B
Spina bifida	741.00-741.93	A
Other congenital anomalies of nervous system	742.0-742.9	A
Congenital anomalies of heart	745.0-745.9	B
Congenital anomalies of respiratory system	748.3-748.9	A
Congenital anomalies of digestive system	751.0-751.9	A
Congenital anomalies of urinary system	753.0-753.9	A
Congenital anomalies of spine	756.1-756.9	A
Chromosomal anomalies	758.0-758.9	B

APPENDIX 11

Entered by:	JTA	Date Last Update:	10/5/2004	Office Hours:	Tg	Languages:
Type of Resource:	Provider			Monday:	8:00	<input type="checkbox"/> English/Other
Resource Name:	Brooklane Health Services Substance Abuse			Tuesday:	7:00	<input checked="" type="checkbox"/> Spanish
Contact Name:				Wednesday:	8:00	<input type="checkbox"/> French
Address:	13218 Brooklane Drive			Thursday:	7:00	<input type="checkbox"/> Korean
City/State/Zip:	Hagerstown	MD	21742	Friday:	8:00	<input type="checkbox"/> Interpreter Provided
Phone/Fax/Email:	301 733-0330		301 733-4038	Saturday:	7:00	<input type="checkbox"/> Sign Language
Comments:	Brooklane is a private not for profit continuum of mental health services. This organization provides quality behavioral health services. The Substance Abuse			Sunday:	7:00	<input type="checkbox"/> Other
<input type="checkbox"/> Mid Capital Area						
Courts Served:	<input checked="" type="checkbox"/> Allegany <input type="checkbox"/> Carroll <input type="checkbox"/> Frederick <input type="checkbox"/> Montgomery <input type="checkbox"/> Talbot <input checked="" type="checkbox"/> Anne Arundel <input type="checkbox"/> Calvert <input type="checkbox"/> Baltimore City <input type="checkbox"/> Harford <input type="checkbox"/> Prince George's <input type="checkbox"/> Washington <input checked="" type="checkbox"/> Baltimore County <input type="checkbox"/> Charles <input type="checkbox"/> Howard <input type="checkbox"/> Queen Anne <input type="checkbox"/> St. Mary's <input type="checkbox"/> Worcester <input checked="" type="checkbox"/> Carroll <input type="checkbox"/> Dorchester <input type="checkbox"/> Kent <input type="checkbox"/> Prince George's <input type="checkbox"/> St. Mary's <input type="checkbox"/> Wicomico <input type="checkbox"/> Calvert <input type="checkbox"/> Howard <input type="checkbox"/> Queen Anne <input type="checkbox"/> St. Mary's <input type="checkbox"/> Talbot					
Eligibility Criteria:						
<input type="checkbox"/> Sliding Scale	<input type="checkbox"/> Sliding Scale			<input type="checkbox"/> DVA funding		
<input checked="" type="checkbox"/> Cost varie	<input checked="" type="checkbox"/> Cost varies depending on program			<input type="checkbox"/> DORS		
<input checked="" type="checkbox"/> Insurance accepted	<input checked="" type="checkbox"/> Insurance accepted			<input type="checkbox"/> Other funding		
Application Process:				<input type="checkbox"/> Varies depending on program		
<input type="checkbox"/> No application needed	<input checked="" type="checkbox"/> Basic application to be completed			<input type="checkbox"/> Age Range:		
<input checked="" type="checkbox"/> Basic application to be completed	<input type="checkbox"/> Varies depending on program			<input type="checkbox"/> All ages are eligible		
<input type="checkbox"/> Varies depending on program	<input type="checkbox"/> Medical documentation must be provided			<input type="checkbox"/> Applicant must have a disability		
<input type="checkbox"/> Medical documentation must be provided	<input type="checkbox"/> Must be completed by person other than family member			<input type="checkbox"/> Financial criteria may be considered		
<input type="checkbox"/> Physician Referral Required				<input type="checkbox"/> Applicant must have specific diagnosis		
				<input type="checkbox"/> Applicant must be Resident of State		
				<input type="checkbox"/> None		
					<input type="checkbox"/> Clear	
					<input type="checkbox"/> submit	

APPENDIX 12



CHI Program for All-Inclusive Care
for Children and Their Families™ (CHI PACC®)

**CHI PACC® Standards of Care
and Practice Guidelines**

A CHI PACC® program provides a continuum of care for children and their families from the time that a child is diagnosed with a life-threatening condition, with hope for a cure, through the bereavement process, if cure is not attained. The CHI PACC® program's integrated, coordinated continuum of care is provided across all settings, 24 hours a day, 7 days a week.

May 2003

CHILDREN'S HOSPICE INTERNATIONAL
901 North Pitt Street, Suite 230
Alexandria, Virginia 22314 USA
1-800-2-4-CHILD www.chionline.org

Introduction

PURPOSE

The CHI PACC® Standards listed below outline basic essential model of care components for the development of local Programs of All-Inclusive Care for Children/Adolescents who are diagnosed with life-threatening conditions and the members of their families. The goal of CHI PACC® is to expand access to curative and palliative services beyond the scope of traditional hospice benefit.

The accompanying CHI PACC® Practice Guidelines represent best practices in the goal of providing optimal curative and palliative care to these children/adolescents and families. CHI PACC® programs are expected to continuously evaluate and improve the quality of the services and supports provided to program participants.

STATUS

CHI PACC® is an authorized demonstration program administered by Children's Hospice International in collaboration with the Centers for Medicare & Medicaid Services (CMS) and the United States Department of Defense. This program provides an opportunity to establish CHI PACC® projects with federal waivers or other mechanisms that remove existing regulatory barriers and redistribute funding.

PROGRAM EXPECTATIONS

The CHI PACC® Standards outline the components of the model of care. CHI expects that programs will establish plans by which the Standards will be implemented in an orderly, timely manner with timelines and measurable objectives.

The CHI PACC® Practice Guidelines outline the components of a fully developed CHI PACC® program. CHI expects that programs will establish plans by which the Practice Guidelines will be implemented in a manner that facilitates the provision of optimal care.

STANDARDS OF CHI PACC®

Implementing CHI PACC® Standards with their accompanying Practice Guidelines will assist CHI PACC® programs to establish health care systems which will help implement the new model of care. The following is a list of the core Standards of the CHI PACC® model, which must be adhered to in the development of any CHI PACC® program.

1. Creation of a continuum of care integrating provider organizations, community-based organizations, professionals and volunteers into one unified interdisciplinary team, providing any medical, nursing, psychosocial, or spiritual service needed for the child or family unit
2. Integration of a curative care with palliative care and community-based supportive services.
3. Establishment of a system of comprehensive care with one point of entry providing a wide range of interdisciplinary services available from the time of diagnosis, onset, or time of referral, through the attainment of cure/remission, the graduation into an adult program of care, or if necessary, the provision of bereavement counseling.
4. Redistribution of funding in order to increase the range of services available in the community and to ensure that the funds follow the child/family into the most appropriate treatment setting.

EXPECTED GENERAL CLINICAL OUTCOMES

The CHI PACC® Standards/Practice Guidelines establish a functional framework in which clinicians are not restricted by artificially limiting provider regulations and reimbursement. This model allows for the development of responsive client-based, client-determined, systems of clinical care with improved clinical outcomes and consumer satisfaction. These outcomes will address:

1. Early implementation of palliative care integrated with medical treatments of the life-threatening condition with the goal of addressing quality of life needs and issues through palliative care.
2. Expanded availability of home and community based services to reduce dependence on institutional care.
3. Enhanced support services to maintain family cohesion, sense of control, satisfaction with care, and informed decision making.
4. Facilitation of transitions from settings of care due to progression of condition.
5. Advanced preparation and support of families when end-of-life care becomes imminent.

EXPECTED FINANCIAL OUTCOMES FOR PAYERS CHI PACC®

The implementation of CHI PACC® programs will have a “cost neutral” impact upon the total expenditures of public and private payers. This will be achieved by cost-offsetting to fund expanded palliative care services through reducing expenditures in the following ways:

1. Preventing unnecessary Emergency Room and Hospital admissions.
2. Facilitating earlier discharges from hospitals into home care.
3. Performing some treatments and procedures, such as chemotherapy, at home.
4. Supporting families to provide end-of-life care at home rather than the hospital, as appropriate.
5. Providing “hospice in the hospital” when it is appropriate for a terminal admission.

TECHNICAL ASSISTANCE

CHI is available to answer any questions regarding the satisfaction or implementation of these Standards/Practice Guidelines. For assistance, please contact CHI at 800-2-4-CHILD, or at info@chionline.org.

DESCRIPTION OF KEY TERMS

All Settings of Care:	Describes any location in which services are provided, such as home, respite facility, hospital, etc.
Child Adolescent	Identifies anyone within program defined guidelines who is eligible for admission to a CHI PACC® program due to diagnosis of a life-threatening condition, regardless of chronological age, developmental stage, or gender.
Comprehensive Care:	Describes broad range of interdisciplinary services available in all settings of care to meet the medical, nursing, psychosocial, spiritual, and practical concerns and needs of those served by a CHI PACC® program.
Concurrent Care:	Care that integrates treatments aimed at cure or disease management with treatments aimed at managing symptoms through palliative care.
Continuity of Care.	Describes consistency in care and services across the entire continuum of care due to the portability of the plan of care and its goals in all settings of care, including ease of transitions from one setting to another.
Continuum of Care:	Describes the “seamless” array of services and providers available from the beginning of care at diagnosis, onset, or time of referral, through the attainment of cure/remission, the graduation to an adult program of care, or the completion of bereavement of care.
Diagnosis of Life-threatening	A formal evaluation made by a licensed physician indicating the existence of a condition that has the potential of limiting the life-expectancy of the Condition: child adolescent.
Disease Treatment:	Medical interventions and procedures implemented by written orders of a licensed physician intended to treat the condition that is threatening the life-potential of a child adolescent, whether the goal is the hope of eliminating the condition, achieving remission of the progression of the condition, or extending the life-potential of the child adolescent without altering the basic underlying condition.
Family:	Identifies those persons who constitute the inner circle of physical, psychosocial, spiritual, and emotional relationships with the child/adolescent who is diagnosed with a life-threatening condition.
Children/Adolescents With Life-Threatening Categories:	Children/adolescents who fall into Conditions: <ol style="list-style-type: none">1. Children/adolescents for whom curative treatments are possible and likely to succeed, and who could benefit from palliative care.2. Children/adolescents for whom curative treatments are possible and fail, and who need palliative care.3. Children/adolescents for whom extensive periods of curative or palliative treatment may extend their lives, even though death is likely.4. Children/adolescents with chronic and/or progressive conditions for which there is no cure and whose treatment is primarily or exclusively palliative.

5. Children/adolescents with severe neurological disabilities causing susceptibility to complications which affect the child/adolescent's ability to function or quality of life, and symptoms causing discomfort

6. Children/adolescents and families who are likely to experience a great deal of distress, disruption and suffering as a result of the condition.

Palliative Care: An approach to provide total comprehensive comfort-oriented care for children/adolescents/families as a whole and whose purpose is to enhance quality of life, minimize suffering, relieve causes of distress, and provide emotional and spiritual support through interdisciplinary services and interventions.

Parent: Identifies the individual(s) who have the legal or guardianship responsibility for the well-being and care of the child/adolescent diagnosed with a life-threatening condition.

Program of All-Inclusive Care: Model of care providing enhanced services to children/adolescents with life-threatening conditions and their families.

CHI PACC® Program: An organized program qualified to participate in the Children's Hospice International demonstration project for children/adolescents diagnosed with life-threatening conditions and the members of their families, abbreviated CHI PACC®.

Referral: The point at which a physician, upon identification of a life-threatening condition, or symptoms of a life-threatening condition affecting the ability of a child/adolescent to function and/or have an acceptable quality of life, contacts the local CHI PACC® program for the child/adolescent to be considered for admission.

Principles of Care

with

Practice Guidelines

ACCESS TO CARE

Principle:

Children and adolescents diagnosed with life-threatening conditions and the members of their families have ease of access to a comprehensive, coordinated, competent continuum of care in their communities.

Practice:

- A C 1. Outreach plans are implemented across all geographic areas in which CHI PACC® programs are available, in order to ensure eligible families, providers, and community organizations have adequate information to facilitate referral to the program. Programs must be comprised of adequate professional medical, social, and supportive staff to serve the needs of those eligible families in the program's service area.
- A C 2. CHI PACC® services are culturally relevant, sensitive, and available to children/adolescents and families of the diverse cultures within the program's service area, and in language that is understandable.
- A C 3. CHI PACC® program provides communication supports to assist children/adolescents and family members that are sensory or cognitively impaired.
- A C.4. The CHI PACC® program provides organized outreach, ongoing education, accurate information about services, and timely resources to all potential referrers to the CHI PACC® palliative care program to enhance their ability to identify potentially appropriate children/adolescents and families for referral.
- A.C.5: Children Adolescents in CHI PACC® Programs have access to treatments and therapies aimed at cure, condition modification or life extension concurrent with and integrated with treatments and services aimed at palliative care goals throughout the entire course of their care.

CHILD/ADOLESCENT/FAMILY AS UNIT OF CARE

Principle:

The CHI PACC® care continuum provides care that is consistently child/adolescent oriented and family-centered in its philosophy, values, practices and operation. All care seeks to support and enhance the life-experience and its quality for each child/adolescent/family unit as defined by their culture, values, beliefs, priorities, circumstances, choices and structure.

Practice:

- U C 1. Care is provided to children/adolescents within the context of each one's age, developmental stage, level of understanding, communication ability, as well as severity of life-threatening condition and its symptomology. Each child/adolescent's own interest, hopes, fears, values, beliefs, and needs are solicited to ensure to the fullest degree possible the integration of the child/adolescent's own point of view and perspective in planning, implementing and evaluating services.
- U.C 2 Care is available to all members of the family according to assessed needs and individual choice, including siblings, parents, grandparents and/or other individuals significant to the family unit.
- U.C.3. Care affirms the uniqueness and distinctiveness of each family's own system of inter-relationships, roles, decision-making processes, and organizational structure.
- U.C.4. Care is implemented to encourage and assist each child/adolescent/family unit to live as normal as is possible under existing circumstances, continue in their customary roles and activities as much as possible and participate in the communities of which they are a part.
- U C 5. Each family unit is assessed in order to establish a plan for meeting the ongoing family member's involvement in caregiving at home. Each family is provided education, training and support for its care giving activities and responsibilities. Careful attention is given to helping families be open to receiving additional support through volunteers, respite care, ancillary staff support, as well as assistance from others in the community

ETHICS

Principle:

The CHI PACC® program operates its services for children adolescents and family members according to generally accepted ethical standards.

Practice:

- E 1. CHI PACC® service staff respect and honor the individuality, uniqueness, and humanness of each child adolescent and family member, ensuring their inclusion in decision-making to the full extent possible, and consistent with the beliefs and values of their culture, spirituality and family structure
- E 2 CHI PACC® program staff ensures the appropriate, necessary, and responsible use of all information about each child adolescent and family member, and protects the confidentiality of all communications, documents, records and materials from unauthorized exposure or use.
- E 3 CHI PACC® service staff ensures that each child/adolescent and family member receives information concerning the life-threatening conditions, diagnosis, condition trajectory, treatment options and their side effects, symptoms and their treatment options and side effects, and their quality of life implications in language understandable to them, and within a supportive respectful communication environment.
- E.4. CHI PACC® program staff ensures that its services are available and accessible to any child/adolescent diagnosed with any life-threatening condition and family members without discrimination for reason of age, gender, racial or ethnic origin, national origin, geographic location in service area, language, religion or spirituality, sexual orientation, diagnosis, disability, family structure or status, ability to pay or potential cost of care to the program.
- E.5. The CHI PACC® service staff implements treatments and services whose intentions are designed to achieve the maximum beneficial child/adolescent and family outcomes possible with the least amount of negative impact possible on quality of life goals.
- E 6 The CHI PACC® program staff insures that its resources provide adequate support for the services provided and the continuing development of the program and an appropriate system of accountability is in place.
- E.7. The CHI PACC® program staff provides an ethics consultation and educational service to assist program personnel, family members and the child/adolescent with a life-threatening condition when there are conflicts about choices for living services and treatments.

MANAGEMENT AND OPERATIONS

Principle:

The CHI PACC® program is a comprehensive integrated continuum of services operating according to nationally recognized standards of care, evidence based treatments, and best practices. It is accountable to all appropriate licensure, regulation, and accreditation bodies and to the communities in which the families and children adolescents live.

Practice:

M.O.1. The CHI PACC® program establishes and maintains current, accurate, adequate and comprehensive management of all aspects of the program, provides all needed services, manages all personnel, coordinates all collaborative relationships, assures fiscal, clinical, and managerial accountability and ongoing evaluation and program improvement and development.

M.O.2. The CHI PACC® program operates within the requirements all local, state and federal laws and regulations that govern the establishment and delivery of CHI PACC® services by various providers, as well as qualifications of professionals and volunteers delivering services.

M.O.3. The CHI PACC® program provides a clear, accessible and responsive grievance procedure for children/adolescents and family members which outlines how to voice concerns or complaints about services and care without jeopardizing their relationship to the CHI PACC® program or access to needed services.

M.O.4. The CHI PACC® program ensures that all personnel, including administrative, managerial, clinical, supportive and voluntary are qualified and oriented for their positions and responsibilities, operate with a current accurate job description, have a designated supervisor/administrator, have access to appropriate support and ongoing training and skills building, and are evaluated on a routine basis by criteria based on their job description and responsibilities.

INTERDISCIPLINARY TEAM

Principle:

Children/adolescents living with life-threatening conditions and the members of their families have a wide range and intensity of ongoing and changing stresses, needs, problems and hopes requiring care. This complex need for care requires the expertise and competence of many disciplines, perspectives and skills working together as an integrated, comprehensive, coordinated team to provide effective care.

Practice:

- I.T.1. The CHI PACC® core team is staffed by an appropriate and representative range of medical, nursing, psychosocial and spiritual professionals, ancillary and support personnel, and volunteers adequate to meet the need for care. The team incorporates and integrates members of many disciplines, and may include pediatricians, pediatric medical and nursing specialists, advance practice nurses, high tech nurses, physician specialists, physician assistants, nurse assistants, social workers, chaplains, home health aides, home makers, in-home respite workers, physical therapists, occupational therapists, speech and language therapists, nutritionists, art therapists, music therapists, play therapists, recreation therapists, pediatric psychiatrists and/or psychologists, massage therapists, and others according to their availability in the program service area.
- I.T.2. The CHI PACC® core team is responsible to provide ease of admission, comprehensive assessments, identification and clarification of goals of care, development and implementation of a current plan of care, facilitate continuity of care in all settings, provide effective symptom management, counseling and supportive services for those it serves, including end-of-life care as appropriate.
- I.T.3. The child/adolescent and family are included as members of the team assigned to their care, and encouraged to manage the care according to their desire and abilities
- I.T.4. The CHI PACC® core team has a qualified medical director, nurse manager and psychosocial spiritual care coordinator/supervisor, and a designated team coordinator.
- I.T.5. The CHI PACC® core team establishes and maintains an effective system to ensure timely sharing of information between all team members and the coordination of services.
- I.T.6. The CHI PACC® core team collaborates and coordinates care with the professionals in other settings
- I.T.7. CHI PACC® core team members are qualified in their particular discipline, role and responsibilities by training and/or experience, and certification and/or licensure when appropriate or required.
- I.T.8. CHI PACC® core team members receive educational, emotional and spiritual support appropriate to their roles and responsibilities, setting of care, and need.
- I.T.9. Essential medical, nursing, psychosocial and spiritual services are available to children adolescents and family members 24 hours a day, each day, in all settings of care.
- I.T.10. In communities in which particular pediatric, medical or palliative care expertise is not available, the team has a documented plan and method to access that expertise

ADMISSION PROCESS

Principle:

The CHI PACC® program maintains a barrier-free process which facilitates ease of entry into the program for children adolescents and their families, timely response to initial and presenting needs and problems, and access to on-call care at the time of admission

Practice:

A.P.1. The CHI PACC® program provides ease of entry into its services for children adolescents and their families and monitors the process of admission, recognizing that at the time of referral, many children adolescents and families may be in crisis and need immediate care.

A.P.2. An initial plan of care is established promptly after admission to guide care and services, (recognizing that it may take time to develop a trusting relationship between the child/adolescent and family and CHI PACC® staff) to assess the comprehensive needs of the child adolescent and each family member, respond to presenting needs or problems, negotiate goals of care, receive, disseminate and evaluate all relevant and necessary information from the child's/adolescent's primary medical team and/or hospital.

A.P.3. The CHI PACC® program acquires all necessary and needed demographic information, relevant medical history, and documentation about disease management and/or medical therapies at the time of referral and admission.

A.P.4. Admission to the CHI PACC® program is made on the basis of the need for care and criteria for CHI PACC® eligibility without regard to age, gender, racial or ethnic origin, national origin, geographic location in service area, language, religion or spirituality, sexual orientation, diagnosis, disability, family structure or status, ability to pay or potential cost of care to the program

A.P.5. CHI PACC® program eligibility criteria are available in language and terminology understandable to nonprofessionals, and family members and available in the primary languages spoken in the service area.

A.P.6. Admission to CHI PACC® program is admission to the entire continuum of care and its comprehensive system of services.

COMPREHENSIVE ASSESSMENT PROCESS

Principle:

Comprehensive interdisciplinary assessment instruments are utilized by the CHI PACC® care team to insure that the goals of care and plan of care are based on needs identified as important to the child adolescent and family. This assessment process is ongoing as needs, circumstances and hopes change during the course of care in response to the progression of the child adolescent's life-threatening condition and its symptomology

Practice:

C.A.P.1. CHI PACC® interdisciplinary staff members assess the comprehensive ongoing physical, psychosocial, emotional, spiritual, practical and financial situations, circumstances, needs, hopes, concerns and goals of each child/adolescent and family member, from the time of admission and continuing throughout the entire course of care, including end-of-life care and bereavement.

C.A.P.2. CHI PACC® team assessments take into consideration the child's/adolescent's developmental stage, spirituality, diagnosis, trajectory of life-threatening

condition, treatment choices and protocols, and progressive symptomology, caused by the progression of the condition or its treatments.

whether

C A P.3. CHI PACC® team assessments are made within the understanding, language, values, beliefs, hopes, family structure and social context of each and family.

culture,
child/adolescent

C.A.P 4. CHI PACC® team assessments are utilized to gather all the information needed for implementing services, and to provide a means for CHI PACC® staff members to build relationships with each child/adolescent and family, offer education and information about choices and options, and provide support

GOALS OF CARE

Principle:

Consistent goals of care guide the establishment and implementation of all services in all care settings and by all providers of services. These goals reflect the culture, hopes, values, beliefs and quality of life needs of children adolescents and their families in response to the assessed situation of the life-threatening condition. The goals are utilized to establish the integrated treatment of the disease or life-threatening condition along with the palliative care plan of care and array of services to be provided. All medical treatment goals and palliative goals are in response to the goals of the child/adolescent/family.

Practice:

G O.C.1 In order for children/adolescents families to formulate reasonable, realistic goals of care within hope for cure, the most accurate truthful information is provided about the condition diagnosed, its symptomology, treatment options and their side effects and expectations, life expectancy, possible family burden, and opportunities for quality of life.

G.O.C.2. The CHI PACC® Interdisciplinary Team collaborates with the primary care/disease management personnel and palliative care personnel to assess each child/adolescent's and family's life goals to offer best practices and supportive services to the child/adolescent and family within the context of these goals.

GO C.3 The CHI PACC® Interdisciplinary Team establishes methods to evaluate, re-assess and adjust both the global and specific goals of care throughout the progress of the life-threatening condition and its care

G O C.4. The CHI PACC® Interdisciplinary Team utilizes the child/adolescent's and family's goals to frame discussions, education, and decision-making regarding the progression of the life-threatening condition, its symptomology, treatment options and achievable results.

G O.C.5 The CHI PACC® Interdisciplinary Team members who are directly responsible for the care of each child/adolescent and family unit, orient staff members in all settings of care to the child/adolescent and family's life goals, disease-treatment goals, and the palliative care goals as settings of care change

G.O.C.6. The CHI PACC® Interdisciplinary Team members responsible for the care of each child/adolescent/family unit ensure that discussions concerning the goals of care and their implications for services are conducted with language and vocabulary understandable to them, are done in a way that empowers the decision making choices of child/adolescent and family, and provides emotional and spiritual support.

G.O.C.7. The CHI PACC® Interdisciplinary Team members responsible for the care of each child/adolescent/family unit recognize that there will be times and occasions in which the child/adolescent and family members will experience ambiguity, conflict and/or unrealistic expectations regarding the goals of care, treatment therapies, and choices available to them, as well as potential differences about those choices, and their potential results. This ambiguity and/or conflict also may be present in the CHI PACC® team members and/or disease treatment professionals as well. Every effort is made to resolve the occasions through processes of mediation, consensus building, and provision of support, counseling and education.

G.O.C.8. The CHI PACC® program provides support to and advocacy for the child/adolescent family when there is a disconnect between the culture, values, and goals of the child/adolescent/family and those delivering services in any setting. A process of mediation and consensus building should be utilized to resolve occasions of conflict over the goals of care and their implications for services, procedures and treatments.

PLAN OF CARE

Principle:

An up-to-date comprehensive written plan of care is individualized to meet the specific needs, hopes and goals of each child/adolescent and family, addresses the medical, nursing, psychosocial, spiritual, and practical concerns and problems they have identified with achievable outcomes and results, and integrates the activity of the team implementing *medical* treatment services and the team implementing *palliative* services.

Practice:

P.O.C.1. The CHI PACC® Interdisciplinary Team establishes a comprehensive plan of care appropriate for each child/adolescent and family based on comprehensive ongoing assessment of needs, hopes and goals identified by the child/adolescent and family unit.

P.O.C.2. CHI PACC® Interdisciplinary Team members monitor the plan of care integrating treatment goals and procedures of the life-threatening condition and palliative care goals and services.

P.O.C.3. The CHI PACC® Interdisciplinary Team ensures that each child/adolescent and family has direct input into the creation and establishment of the plan of care.

P.O.C.4. The CHI PACC® plan of care identifies a family member and a CHI PACC® team member, as the point of contact for the coordination of services and care, and the resolution of problems.

P.O.C.5. The CHI PACC® Interdisciplinary Team monitors, reviews and revises each plan of care on a regular and ongoing basis as goals, needs and hope change and the disease and symptoms progress.

P.O.C.6. The CHI PACC® Interdisciplinary Team establishes mechanisms to ensure the portability of the plan of care in all settings of care and communication with staff members of the plan of care when a change in the setting of care occurs

P.O.C.7. The CHI PACC® program ensures that appropriately signed consents are negotiated and documented for the initiation or withdrawal or withholding of treatment

CONTINUITY OF CARE

Principle:

CHI PACC® service delivery is based on a therapeutic relationship between child/adolescent, family members, and CHI PACC® team members. It maintains an integrated coordinated continuum of community based home care, out patient services, respite care, supportive services, primary medical and inpatient care, end-of-life care, and community services. The CHI PACC® team ensures continuity and consistency of care, in any setting, is provided from the time of admission to the conclusion of bereavement services or discharges from the program and provides a system of care management to assist each child/adolescent family unit. This continuity also extends to relationships important to the child/adolescent and family, such as school, religious affiliation, and community activities.

Practice:

C.C.1. CHI PACC® medical, nursing, psychosocial and spiritual care is available on a consistent basis, 24 hours a day in all settings of care, to child/adolescent and family members

C.C.2 Appropriate members of the CHI PACC® program are available to children adolescents and families at all times when the office is closed.

C.C.3 The CHI PACC® program has a communication system that ensures the confidentiality and privacy of child/adolescent and family information, can be used to update team members about each child adolescent's and family's status, and facilitates a timely response to changing needs and or problems.

C.C.4. The CHI PACC® program has a functioning continuum of care that ensures the portability of goals of care and the plan of care, and access to needed services as settings of care change

C.C.5. The CHI PACC® program maintains all required and appropriate documents and clinical records, maintains their confidentiality, ensures their safety, and appropriate clinical use.

C.C.6. The CHI PACC® program has written policies and procedures for transitioning a child adolescent who reaches adulthood and the family to the new legal status of the child adolescent, which includes continuity with changes in providers, payer sources, status of legal documents, and treatment options and choices.

SYMPTOM MANAGEMENT

Principle:

The range and intensity of symptoms which cause distress to the child/adolescent and family are managed to achieve the most attainable quality of life for child/adolescent and family within the context of their culture, beliefs, values and goals. Children/adolescents and their families must have access to care which is both competent and compassionate.

Practice:

S.M.1 The CHI PACC® Interdisciplinary Team assesses all symptoms which cause distress or discomfort, whether as the result of progression of the life-threatening condition or its treatment

S.M.2 The CHI PACC® Interdisciplinary Team identifies each distressing symptom, such as pain, dyspnea, fatigue, loss of appetite, loss of body image, constipation, diarrhea, vomiting, and loss of sleep and assesses each for its etiology, best practice evidence-based treatments, and range of choices for treatment.

S.M.3. The CHI PACC® Interdisciplinary Team members discuss, evaluate and implement complementary, alternative and culturally relevant therapies and treatments important to children/adolescents and their families as appropriate to enhance the therapeutic environment.

S.M.4. Members of the CHI PACC® Interdisciplinary Team provide clear, accurate information about evidence-based treatments and alternatives as objectively as possible to each child/adolescent and family to assist them in making the most appropriate choices for treatment options according to their own values, beliefs and goals.

S.M.5. The CHI PACC® Interdisciplinary Team encourages consistency of symptom management services and treatments in all settings of care by all providers of care.

S.M.6. The CHI PACC® program has clinical expertise through a competent medical and nursing staff to provide effective state-of-the-art symptom management, and access to specialists as may be required or needed.

COUNSELING AND SUPPORTIVE CARE

Principle:

The diagnosis of a child adolescent at any age or stage of development with a life-threatening condition initiates a life-changing crisis within the family that turns their world, customary roles, activities, assumptions and expectations of each member "upside down." These children/ adolescents and family members must have access to a comprehensive, coordinated, competent continuum of counseling and supportive services to assist them with the physical, emotional and spiritual issues, interpersonal dynamics and psychosocial dimensions of their experience.

Practice:

C.S.C.1. The CHI PACC® Interdisciplinary Team identifies the initial ongoing and changing physical, psychosocial, emotional and spiritual issues, concerns, conflicts, priorities and needs of each child/adolescent and family member, and evaluates each for the most appropriate response, integrates this into and plan of care, and assigns appropriate team members to assesses the written goals implement services.

C.S.C.2. The CHI PACC® program does not require or advocate a "right way" for children adolescent and a family member to believe, cope, make decisions, grieve, or die but recognizes the deeply personal and individual nature of this experience. CHI PACC® team members provide counseling and supporting services which build upon each family member's own emotional and spiritual strengths, coping mechanisms, priorities, communication styles, belief and value systems, cultural and ethnic values, and social resources.

C.S.C.3. The CHI PACC® program facilitates the provision of adequate counseling and supportive services in all settings of care

C.S.C.4. The CHI PACC® program has clinical expertise through competent counseling, social work and chaplain staff, as well as childlife and childcare specialists.

VOLUNTEER SERVICES

Principle:

Trained and screened volunteers provide an opportunity for members of the community, including children and adolescents, to become directly involved in the care of children adolescents living with life-threatening conditions, their families and the bereaved, as well as to serve the CHI PACC® program in other supportive and organizational capacities

Practice:

- V S.1 The CHI PACC® program has a structured, organized and active volunteer program adequate to support the care needed by children/adolescents and their families, as well as to meet other needs within the CHI PACC® program for volunteer support.
- V S.2. The CHI PACC® volunteer program is managed by a designated, qualified supervisor/coordinator that is a member of the CHI PACC® Interdisciplinary Team and meets regularly with them.
- V S.3. CHI PACC® program volunteers are considered non-salaried staff members and are managed and supervised accordingly.
- V.S.4. All volunteers are appropriately recruited, screened, trained, assigned, supervised and evaluated on the basis of their roles and responsibilities.
- V.S.5. Volunteers may include children and adolescents.
- V.S.6. CHI PACC® volunteer services to children/adolescents and families are initiated according to the assessed need and consent of the child/adolescent and family
- V.S.7. CHI PACC® volunteers have access to an organized program of ongoing education and support.
- V.S.8. CHI PACC® volunteer services are documented and reports provided on kinds of services provided, hours of services provided and other activities undertaken, as well as the financial value of these services to the program.

BEREAVEMENT PROGRAM

Principle:

Family members of children adolescents who die may continue to need supportive and or professional services following the child's adolescent's death for a period of time that varies among families and family members. The overall goal of bereavement care is to assist family members to reintegrate themselves into the communities of which they are a part and to find their long-term support in their communities.

Practice:

- B P 1 The CHI PACC® program has a structured, organized, adequate program of bereavement services for surviving family members and or significant others, including linkage to support organizations and services in the community.
- B.P.2. The CHI PACC® bereavement program is managed by a designated, qualified supervisor coordinator who is a functioning member of the CHI PACC® Interdisciplinary Team and meets regularly with them.
- B.P.3 The CHI PACC® bereavement program has professional and or volunteer staff members adequate and competent to meet the range of services needed by family members, including siblings.
- B.P.4 The CHI PACC® Interdisciplinary Team members who were involved in the care of families before the child died provide an assessment of the level of risk and need for services of the bereavement program by family members.
- B.P.5. All CHI PACC® professional and volunteer staff members in other settings of care have access to bereavement services as needed.
- B P 6 The CHI PACC® bereavement program establishes a written bereavement plan of care based on an assessment of needs for each family member receiving bereavement services until the person is discharged from the program.
- B.P.7. The CHI PACC® bereavement team members have access to an organized program of education, supervision, support and evaluation.
- B.P 8 CHI PACC® bereavement services are documented and reports provided on services and their utilization.

RESEARCH & EVALUATION

Principle:

The CHI PACC® care program acknowledges the importance of developing evidence to support the most effective care practices for children, families, providers, and health systems concerning comprehensive services for children diagnosed with life-threatening conditions and their families. CHI PACC® programs accept the responsibility to participate in a variety of research activities, including those that may have scientific value or others that may guide program improvements or meet reporting requirements. These diverse research activities will occur in community and clinical care settings, and shall extend to bereavement services as appropriate. While these research activities may vary in methodology and setting, they will all provide opportunities for patients, families and providers to assess the performance of programs and services in systematic, confidential, and valid ways. These research activities will share the general purposes of improving the quality of pediatric care and promoting optimum outcomes for patients, families, providers, and health systems. These research efforts will strive to be culturally competent and family-centered in their approach to conceptual and measurement issues. Because of the need to generate new knowledge in this area, CHI PACC® programs further accept the responsibility to protect the rights of patient privacy and to understand and guard against any potential harm, including psychological burden, to families and patients who participate in ongoing research and/or evaluation activities.

Practice:

- R.E.1. The CHI PACC® program has a defined and timely research agenda, plan, and structure for implementation.
- R.E.2 The CHI PACC® program staff at all levels is educated to the importance and necessity of research, its different approaches and methods, and requirements for the protection of human subjects. CHI PACC® program staff also is encouraged to initiate and/or participate in research activities.
- R.E.3. The CHI PACC® program provides resources to support the research activities it undertakes.
- R.E.4. The CHI PACC® program encourages research collaborations locally and nationally to expedite the process of generating new knowledge and establishing clinical consensus.
- R.E.5. The CHI PACC® program has an organized and effective way to facilitate communication and sharing of tools and knowledge to others who are providing comprehensive pediatric care, including palliative and end-of-life care.
- R.E.6. The scope of outcomes that are relevant to the quality of care in pediatric services include outcomes across the care continuum and extend to bereavement care. The focus of outcomes are broad and span patient and family satisfaction, quality of life, provider satisfaction, cost-effectiveness, clinical performance, and health systems change.
- R.E.7. The CHI PACC® program participates in national cross-site type evaluation studies as needed and supports the collection of nationally-based data, criteria, and evaluation information over and above information needed for program specific goals.
- R.E.8. The CHI PACC® program has methods and procedures for monitoring, evaluating and improving its performance in meeting its most fundamental assumptions of access to a continuum of integrated disease management and palliative care from the time of diagnosis, with hope of cure, until the time of discharge from the program, as well as

consistency of care across all settings of care and cost effectiveness.

R.E.9. The CHI PACC® program has an organized, effective and consistent way in which professional and volunteer staff members evaluate the effectiveness and adequacy of its policies and procedures, outreach, services, programs, management, and governance.

R.E.10. The CHI PACC® program has an organized, effective method by which primary care pediatricians, professionals in disease and treatment, and key staff members in other collaborative settings and/or programs of care evaluate the effectiveness of the CHI PACC® program, its operation and services.

R.E.11. The CHI PACC® program provides all reports, data and documentation required by funders and constituents in a timely, accurate manner.

R.E.12. The CHI PACC® program participates in all required activities which foster the development and expansion of the national CHI PACC® model.

R.E.13. The CHI PACC® program has an up-to-date written program for program improvement and utilization review.

GOVERNANCE AND ADMINISTRATION

Principle:

The governance and administration of, or for the CHI PACC® program, establishes, supports, and develops the program as a priority to meet the needs of children/adolescents and families in the community and or region it serves. Governance may be achieved through an independent Board of Directors or an Advisory Board.

Practice:

G.A.1 The governance structure for the CHI PACC® program insures that its mission, vision, general policies, and range of services implement the national CHI PACC® program standards to meet the needs of children adolescents with life-threatening conditions and the members of their families in the program's service area.

G.A.2. The governance structure of the CHI PACC® program includes a broad representation of its service area, including diverse community representatives, professional and or industry representatives, and children/adolescents and family members, while protecting against incurring conflicts of interest.

G.A.3. The governance structure of the CHI PACC® program insures the integrity and functioning of the CHI PACC® program by providing the level of resources necessary to provide the level of care, mix of services, and range of collaboration needed to meet the needs of children/adolescents and families throughout its service area

G.A.4 The CHI PACC® program director is accountable to an appropriate institutional administrator or governance structure.

G.A.5. The administration and organizational structure of the CHI PACC® program is adequate and appropriate for its mission, principal functions, goals and objectives, requirements for services, and size of program.

G.A.6. The CHI PACC® program has suitable, adequate, appropriate space, work and service environments, equipment, supplies, security and safety systems, communication systems, and other essential resources

G.A.7. The governance and administration of the CHI PACC® program participates in the ongoing development, refinement, and positioning of the CHI PACC® model and vision of care for children/adolescents and their families.

APPENDIX 13

Military OneSource System Analysis Report

Background Information

On June 17, 2004 an onsite visit was made to the Ceridian office in Plymouth Meeting, Pennsylvania for the purpose of understanding the Military *OneSource* Program available to active military personnel. Military *OneSource* is a program administered by Ceridian to assist active military members and their families in locating resources and services to meet any needs they may identify. The primary role for Military *OneSource* is to provide education and options for potential resource supports.

The site visit included spending the day with Ronald White, Director for Military Program Management and Dan Lafferty, Clinical Supervisor for the program. Mr. White has an extensive background in social work as well as international experience related to information and referral supports. Mr. Lafferty is a licensed social worker with certification as an Employee Assistance Professional with military experience in the Air Force. Both have expert experience in the area of employee benefits.

In addition to providing services for the military, Ceridian serves over 10,000 organizations internationally, which translates to over 10 million employees. This Employee Assistance Program (EAP) benefit has been phased in to the various branches of the military over the past four years and is currently available to the Army, Marine Corps, Air Force and Navy. Mr. White estimates that 2.6 million individuals in the military have access to this benefit. Extensive and active marketing campaigns have been implemented to ensure awareness of the service as well as information about its use. Utilization data is tracked and sorted by service branch and reviewed to identify areas for further marketing opportunities for Ceridian.

During the visit, Ceridian personnel emphasize the company's commitment to meeting the needs of the population as it operates an extensive quality assurance program that is evident throughout the facility and through interviews with various personnel.

In an effort to build a collaborative relationship between Military *OneSource* and the project team, Carol Marsiglia led a discussion regarding the *mCare* Project. Juli Lausch prepared an extensive list of questions to be addressed throughout the tour and again at the end of the day. Deona Howard also attended the day. The discussion included an overall description of the project and phases for development of a model of care for children of military families who have life threatening conditions. In addition, use of community and military resources was emphasized to identify areas of potential interface between Ceridian services and needs of the population. Mr. White indicated a

willingness to support the project through the use of Ceridian services. The role of the company as it relates to Military *OneSource* is that of referral and education. Therefore, it is important to note that accessing services identified by Ceridian is the responsibility of the military personnel seeking assistance and beyond the scope of service provided by Ceridian.

There are three Ceridian service centers in the United States that serve the military at home and abroad. These offices are located in Plymouth Meeting, PA, Minneapolis, MN and Miami, FL. The Plymouth Meeting and Minneapolis locations are described as mirror images of each other with Miami specializing in multilingual and multicultural services. All locations have access to a translation service.

Tour of Service Center

Information Technology and Telecommunications

Jo-Anne Mullen, Director and Jerry McDonnell, who are ultimately responsible for the overall security of the data system, presented an overview of the Information Technology and Telecommunications Center. A predictive algorithm is used to process calls to ensure efficiency in answering call volume. The time standard set to respond to a call is 20 seconds with no automated answering system used. The calls are answered by a trained triage specialist who then forwards the calls to the appropriate content specialist. There are over 200 phone numbers used to access the organization's services. International access is available and the organization accepts collect calls.

Mullen and McDonnell described an extensive disaster plan and reported that it is tested regularly. They stated that in the event of a disaster, all calls can be moved to an alternate center through "5 key strokes" and that this is a transparent process to the caller. As part of the disaster plan, a redundancy plan is in effect. All data is replicated at the Minneapolis center allowing consultants at other centers to access all data information necessary for business continuity, as well as storage of backup at an alternate location in Louisville, Kentucky. Backups occur multiple times throughout the day.

In addition to telephone based communications, the service is web based and operates on multiple servers that are reportedly able to handle extremely high volume loads with no evidence

of performance problems. Utilization trends are reported to vary with the Army population, in that 70 % of requests are received via Internet with 30% via telephone. The other military branches are reported to be approximately 80% Internet with 20% telephone requests.

Mr. White indicates that they anticipate greater Army telephone usage over time, similar to other organizational patterns. Generally, utilization reporting is based on service type, location, and demographics such as military grade and family member using the service. Custom reports can be designed and provided upon request.

Fulfillment Center

The Fulfillment Center houses educational materials and publications that are provided to the Ceridian consultants to meet the needs of the individuals making information requests. Information distributed has been developed by or cited from experts in a particular content area. For military specific content, such as items that can be sent overseas, military personnel review the information. For more generic topics, such as coping with stress, only information validated by experts in the field is used. Some publications can be reproduced within the Fulfillment Center and some are purchased for distribution.

Service Delivery/ Research

Masters level consultants handle all calls for Military OneSource and the staff is configured into teams. Clinical Supervisors are responsible for Consultant Teams and are to be notified of all situations defined as significant. Examples of these would include such issues as domestic, child or elder abuse, as well as concerns that have legal implications. The Clinical Supervisor is then responsible to ensure that all actions and resources have been provided to the requestor to address the issue. In addition, the Clinical Supervisor is responsible for reviewing two cases per month for each Consultant on their team as a part of the quality assurance process for services.

Call information such as demographics and requests are documented in the Case Management System, which is a custom developed software system used by the Ceridian staff. The software is an integrated system that communicates with scheduling for tracking purposes, reporting for utilization and communication with Fulfillment area as well as with other members of the service delivery team. During normal business hours, calls are triaged and assigned to Consultant Specialists or Consultant Generalists, dependant upon caller needs. During non-business hours, calls are handled by Consultant Generalists and assigned as necessary to specialists. Calls are accepted 24

hours per day, 7 days per week and 365 days per year. Consultant Specialists are available in the area of adoption, childcare, disability, education and international resources. All other topics are handled by Consultant Generalists. Consultants use an internal database of existing resource information or they send a request to a researcher for more specific information. The researcher also has access to an internal database of resources, as well as an Internet capability search. The researcher can utilize multiple strategies to access information requests. All information for contact is validated by the researcher prior to submission back to the consultant for distribution to the requester. For health specific information, researchers are expected to use web sites that are credible based on their URL including "edu", "gov" or "org".

The service center itself is a rather large area of individually divided workspaces separated by low level partitions, each equipped with a desk computer and telephone. The area is remarkably quiet despite the constant communication between requesters of information and Consultants. Each Consultant wears earphones and therefore no telephone tones are overheard in the work areas.

The service delivery system is currently in the process for accreditation by the Commission on Accreditation.

Quality Management

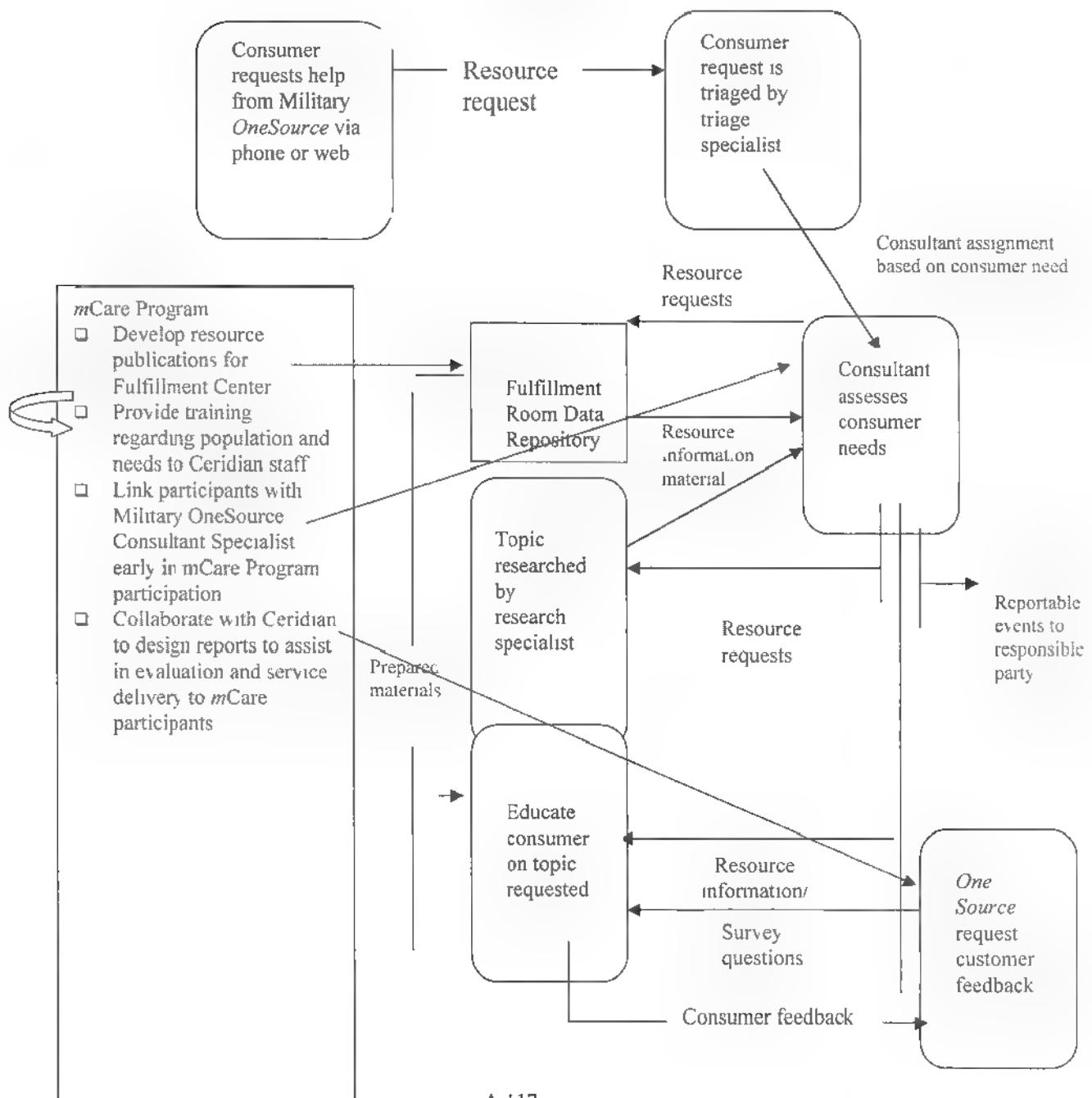
An emphasis on quality is evident throughout the organization as demonstrated by real time data and quality targets posted throughout the service center. These quality targets include answered calls, average hold time and calls abandoned. Goals that are below target are shown in red while on target goals are green. Diane Opere is a manager in Quality Services. She explained that user feedback is extremely important to the organization and is measured through various modes. There is an Interactive Voice Audit Survey and an online survey offered to all customers. The Interactive Voice Audit System allows the customer to answer survey questions in an anonymous way. The online survey is sent 1 week following intervention by Military *OneSource*. Overall return rates are reported at 25% for telephone audit and 28% electronically. Under certain circumstances, referral options are tagged "do not use" based on responses from consumers. Customer feedback reports are submitted to clinical supervisors on a monthly basis. Cendian reports that they are currently working with the Military Research Center at Purdue relative to outcome measures. The company is currently attempting to demonstrate outcomes such as time saved and decreased stress in seeking resource information. Next generation outcome work will be geared toward measurement

of military readiness and retention. Cenidian is reportedly considered a business associate as it relates to the Health Information Accountability and Portability Act (HIPAA).

Recommendations

- Incorporate use of Military *OneSource* Program in future program model to support access to military and community resources as well as general educational information on family related topics.
- Identify information topics that apply to children with life threatening conditions for inclusion in Military *OneSource* databases
- Collaborate with Cenidian to incorporate publications that target the needs of children with life threatening conditions, specifically including CHI publications relating to palliative care
- Identify additional resource linkages to Military *OneSource* that are specific to the *mCare* population.
- Offer training for Military *OneSource* Supervisors, Consultants (general and specialist) and researchers regarding *mCare* population.
- Consider reporting needs for *mCare* population and collaborate with Cenidian to submit reports for targeted population
- Incorporate Health on the Net Code Guidelines related to the distribution of medical and health specific information to ensure credibility and quality.
- Identify any issues related to HIPAA regarding the distribution of resource or health information as it relates to model/program design
- Educate families participating in *mCare* on the benefits of telephonic mode to promote comprehensive response to the needs request.
- Address the gap regarding accessing services as it relates to the education and resource information role of Military *OneSource* verses more intensive care coordination.
- Develop a means to measure outcomes related to the use of Cenidian services with the *mCare* population

Data Flow Diagram
Military OneSource Process for Resource Information Requests



APPENDIX 14

Process breakdown for accessing resources

Process Task	Vulnerabilities	Considerations for Process Improvement
<i>Request a resource</i>	<ul style="list-style-type: none"> • Miscommunication regarding type of resource requested • Resource requested does not meet the need of the child/family • Lack of knowledge on requestors part related to type of resource needed or what may be available 	Areas to be addressed in new model design to be identified as project develops with information obtained within focus groups
<i>Research resource options</i>	<ul style="list-style-type: none"> • Resource information obtained is inaccurate or lacks correct contact information • Resource information obtained does not adequately represent what was requested 	
<i>Apply for resource</i>	<ul style="list-style-type: none"> • Application requires specific information that is not readily available to applicant • Application requires signature from other entity such as physician, or other professional requiring additional steps prior to completion • Application requires multiple estimates for the service requested • Poor or no direction for application completion • Application is denied based on information presented • Application gets lost during process • Application is too complex for family to complete 	
<i>Identify provider for resource</i>	<ul style="list-style-type: none"> • Provider will not accept reimbursement amount or method • Unable to find a provider • Provider of low quality 	
<i>Locate funding source</i>	<ul style="list-style-type: none"> • Unable to identify funding for resource • Not medically necessary resource • End of budget year request that will be postponed for funding in the upcoming fiscal year • 	
<i>Deliver resource or service</i>	<ul style="list-style-type: none"> • Resource is never delivered • Resource or service is delivered but is of poor quality 	
<i>Reimburse for resource or service when applicable</i>	<ul style="list-style-type: none"> • Funding is delayed due to internal processes of funder • Reimbursement is required prior to service delivery • Service provider is not part of network for reimbursement 	↓

APPENDIX 15

Proposed Outcomes and Outcome Indicators for CHI PACC® Programs

Draft August 24, 2004

Prepared by Zohreh Saunders for Children's Hospice International (CHI)

Introduction

The proposed CHI PACC Program Outcomes that are delineated in this document are based on discussions held in the workgroups at the May 2004 CHI PACC Demonstration Program Meeting. The outcomes are grouped into four domains:

- Access
- Coordination
- Family Satisfaction and Stability
- Cost Effectiveness

These domains correspond to the major goals of the CHI PACC Programs. A total of 18 proposed outcomes are grouped under these domains and these are further categorized into 26 measurable outcome indicators in the tables in the attached document. Sources of data and suggested collection methods are also indicated in the table.

The outcomes measures address the major goals of the CHI PACC programs to change the infrastructure, increase early access, coordination and support for the child with life threatening conditions and their families. Because families played such an integral part in designing the CHI PACC programs, their satisfaction is a critical and important part in the outcomes of these programs. It is important to know if the structural changes improve family satisfaction (including the child) and stability. Only two outcome measures address clinical issues i.e. pain and symptom management and competence and sensitivity of care givers as these are central issues in the care of children with life threatening conditions. When educational programs for providers become more widely available (CHI hopes to cosponsor provider training with the Initiative for Pediatric Palliative Care (IPPC) and other organizations in the near future), it may be more meaningful to evaluate improvements in their approach to the child and family and the families perception of its effectiveness.

Process to Review, Adopt, and Implement Outcome Measures

The development of these proposed outcome measures is only the beginning of the process. The number of measures, the form and wording, the percentages, when and how the outcomes will be measured are all up for discussion and change.

The goal is that at the end of the process, there is consensus on 15 to 20 outcome measures that all programs can reasonably assess and measure, using defined data and a comparable method of collecting and reporting the outcomes. Of course CHI PACC programs are encouraged to develop other outcome measures and methods of assuring the quality and effectiveness of their programs that may be more specific to their own programs and program goals, but there should be a core set of measures that are commonly applicable and that all CHI PACC programs can agree to assess. These core measures will also be used to evaluate the success of the CHI PACC programs as a whole.

In the process, it will be important to know what CHI programs are currently doing to evaluate their programs, assure quality, monitor and improve performance. It will also be important to assess surveys and other instruments that are currently being used to determine their usefulness and applicability to all of the CHI PACC programs.

The following process to review, adopt, and implement outcome measures is recommended:

1. Disseminate the proposed outcome measures to all CHI PACC programs for review, comment, suggestions for new outcomes, deletion of others, changes in wording, etc.
2. Form a small committee made up of a few representatives from the CHI PACC state/regional programs, DOD, CMS, and CHI staff or consultant with expertise in evaluation, data gathering, research, etc
3. Use this group to evaluate the comments and suggestions received from all who responded to the initial draft. The group would also investigate existing survey tools and methods.
4. Further refine the measures, including definitions, and more specificity on data sources and survey methods

5. Circulate the revised draft document to all CHI PACC programs to obtain consensus on the core outcome measures and methods
6. Design detailed definitions, targets, survey questions, and procedures, reporting times and process, resources needed, etc.
7. Determine cost and identify resources or obtain needed funds for the process.
8. Circulate for final approval.
9. Secure needed funds
10. Implement.

Proposed CHI PACC Program Outcomes

Access

Establish a system of comprehensive care with one point of entry providing a wide range of interdisciplinary services available from the time of diagnosis, onset, or time of referral, through the attainment of cure/remission, the graduation into an adult program of care, or if necessary, the provision of bereavement counseling.

1. *Families of children with life threatening conditions receive information about the CHI PACC program in their locality at the time of diagnosis of the condition.*
2. Providers who treat the child with a life-threatening condition know how to refer the child to the CHI PACC program serving their area.
3. The CHI PACC program meets its annual enrollment targets.
4. The child and family receive all needed services identified in the plan of care
5. Services that are identified in the plan of care are received in the location preferred by the family.

Coordination

Create a continuum of care integrating provider organizations, community-based organizations, professionals and volunteers into one unified interdisciplinary team, providing any medical, nursing, psychosocial, spiritual service needed for the child or family unit

1. Children in the program have access to a care coordinator or case manager who coordinates care across all needed health care settings.
2. Children in the program have an individualized plan of care, developed by an interdisciplinary team, including the parent and child/adolescent, when appropriate.
3. Providers involved in the child's care operate within the guidelines of the plan of care.
4. The curative and palliative care needs of the child and support of the family caregivers are addressed in the plan of care.

Family Satisfaction and Stability

Enhance opportunities for the child with the life-threatening condition to live as normal a life as possible including prompt management of pain and symptoms, support to enhance family stability, cohesion, informed decision making, and satisfaction.

1. The family has the information needed to make decisions about their child's care.
2. The child's pain and other symptoms are effectively controlled at home and in other settings.

3. The family has adequate support to manage their child's care and maintain as normal a life as possible for all the family members during the course of the illness.
4. Persons providing care are competent and sensitive to the needs of the child and family.
5. At the end-of-life, the child and family preferences are honored.
6. Families whose child dies are offered counseling and bereavement services.

Cost Effectiveness

Redistribute funding in order to increase the range of services available in the community and to ensure that the funds follow the child/family into the most appropriate treatment setting.

1. Choice and access to more integrated and appropriate care will result in changes in service utilization patterns.
2. The average cost of care for children enrolled in the CHI PACC program will not exceed the cost of care without the program.

Proposed CHI PACC® Program Outcome Indicators, Data Sources, Collection Methods

Draft August 24, 2004

Access

Establish a system of comprehensive care with one point of entry providing a wide range of interdisciplinary services available from the time of diagnosis, onset, or time of referral, through the attainment of cure/remission, the graduation into an adult program of care, or if necessary, the provision of bereavement counseling.

A	Access	Outcome Indicators	Source of Data	Method to Collect
1	Families of children with life-threatening conditions receive information about the CHI PACC program in their locality at the time of diagnosis of the condition.	80% of families referred to the program report they received information about the CHI PACC program in their locality within 3 months of receiving their child's diagnosis.	Parent/family caregiver	Enrollment application or enrollment interview.
2	Providers who treat the child with a life-threatening condition know how to refer the child to the CHI PACC program serving their area.	-90% of pediatric physician specialists or clinicians affiliated with the local children's hospital report they received information about the CHI PACC program in their area. -80% of the pediatric physician specialists/practices know how to refer children they serve to the program.	Pediatric physician specialists	Annual survey of pediatric physician specialists and their clinics.
3	The CHI PACC program meets its annual enrollment targets.	By the 3rd year of the CHI PACC program, enrollment targets for the program will be within 90% of the anticipated enrollment figures. -The enrollment of children in urban and rural areas will mirror the distribution of the service area. -The enrollment of minority children will mirror the distribution of the service area. -The enrollment will reflect a mix of the major diagnostic categories including cancer, congenital conditions, and perinatal conditions	Enrollment Data	Information obtained from enrollment information, county/address, diagnosis, racial or cultural identity
4	The child and family receive all needed services identified in the plan of care.	90% of families report the child and family received all needed services identified in the most recently completed plan of care.	Parent/family care giver	Annual survey of enrollees.
5	Services that are identified in the plan of care are received in the location preferred by the family.	90% of families report services identified in the plan of care were received in their preferred location	Parent/family care giver	Annual survey of enrollees.

Coordination

Create a continuum of care integrating provider organizations, community-based organizations, professionals and volunteers into one unified interdisciplinary team, providing any medical, nursing, psychosocial, spiritual service needed for the child or family unit.

C	Coordination	Outcome Indicators	Source of Data	Method to Collect
1	Children in the program have access to a care coordinator or case manager who coordinates care across all needed health care settings.	100% of the CHI PACC program enrollees are offered case management or care coordination services.	Parent or Enrollment Process	Enrollment survey or enrollment records
		95% of the CHI PACC program enrollees know the name of their care coordinator or case manager and how to contact them.	Parent	Annual survey of enrollees.
2	Children in the program have an individualized plan of care, developed by an interdisciplinary team, including the parent and child/adolescent, when appropriate	90% of the CHI PACC program enrollees report the service of the case manager or care coordinator is helpful to them.	Parent	Annual survey of enrollees.
3	Providers involved in the child's care operate within the guidelines of the plan of care.	100% of CHI PACC program enrollees have an individualized plan of care.	Plan of Care	Inspection of the plan of care
4	The curative and palliative care needs of the child and support of the family caregivers are addressed in the plan of care.	100% of the plans of care are signed by at least 3 members of the interdisciplinary team and the parent/caregiver.	Plan of Care	Inspection of the plan of care
		A sample of providers identified in the plan of care have access to the plan of care.	Providers	Random provider calls or review of distribution process
		A sample of providers identified in the plan of care are aware of the plan and their role.	Providers	Random calls to providers
		95% percent of plans of care address both curative and palliative care needs of the child and support of the family.	Plan of Care	Inspection of the plan of care

Family Satisfaction and Stability

Enhance opportunities for the child with the life-threatening condition to live as normal a life as possible including prompt management of pain and symptoms, support to enhance family stability, cohesion, informed decision making, and satisfaction.

F	Family Satisfaction & Stability	Outcome Indicators	Source of Data	Method to Collect
1	The family has the information needed to make decisions about their child's care.	90% of families report they are satisfied with the information needed to make decisions about their child's care (complete, accurate, frequent, sensitive)	Parent/family care giver	Family Survey
2	The child's pain and other symptoms are effectively controlled at home and in other settings.	90% of families report they are satisfied with the pain and symptom control efforts at the home, hospital, and other settings	Parent/family care giver	Family Survey
3	The family has adequate support to manage their child's care and maintain as normal a life as possible for all the family members during the course of the illness.	90% of families report they received supportive services beyond the curative and palliative care offered to the child, such as respite, child care, transportation, counseling, sibling support, costs of care, other.	Parent/family care giver	Family Survey
4	Persons providing care are competent and sensitive to the needs of the child and family.	90% of families report persons providing care to the child and family were competent and sensitive (home, hospital, other setting)	Parent/family care giver	Family Survey
6	At the end-of-life, the child and family preferences are honored.	90% of families report that at the end-of-life, the child and family preferences were honored	Parent/family care giver	Family Survey
7	Families whose child dies are offered counseling and bereavement services	95% of families whose child dies are offered counseling and bereavement services.	Parent/family care giver	Family Survey

Cost Effectiveness

Redistribute funding in order to increase the range of services available in the community and to ensure that the funds follow the child/family into the most appropriate treatment setting.

E	Cost Effectiveness	Outcome Indicators	Source of Data	Method to Collect
1	Choice and access to more integrated and appropriate care will result in changes in service utilization patterns.	More support services such as respite, extended nursing care, counseling, etc. are available to the child and family after program implementation than before.	Waiver or other authorization document.	Review and inspection. Claim data queries
2	The average cost of care for children enrolled in the CHI PACC program will not exceed the cost of care without the program.	Average cost of providing needed services for the enrolled population will not exceed the average cost of providing services for a non-enrolled or historically comparable population.	Hospital/nursing facility claims, historical claims data, or medical records	Claim data queries

Data Collection Source and Methods

Parents	Enrollment Survey Satisfaction Survey End-of-Life Survey
Providers	Survey of Pediatric Physicians and Clinics Call/Questionnaire re: plan of care
Program Records	Waiver or other funding authorization documents Enrollment records (number, age, county, diagnosis, ethnic/cultural identity, date of enrollment, death/disenrollment, place of death) Enrollment protocols Plan of Care
Claims Data	Annual service utilization, units, paid amounts by enrollee, group by diagnostic group or other distinguishing category